Introduction

In this chapter, we propose a framework of citizenship for people with mental illnesses to achieve community inclusion and full participation in society. As with positive psychology, citizenship-oriented mental health care represents a paradigmatic shift away from a pathology-focused approach that may contribute to people’s isolation from their communities. We consider people’s exercise of the rights and responsibilities of citizenship in the context of adequate resources, in possession of valued social roles, and with positive relationships and social networks as a pre-condition for recovery, rather than an eventual reward contingent on overcoming one’s disability. We argue that people’s lived experience of regaining a sense of citizenship and of belonging to their local neighborhoods, communities, and society as a whole can help foster an evolution from disease management to health promotion and community inclusion.

The World Health Organization (WHO) defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 1946). We suggest that attention to linkages between citizenship, mental health, and positive psychology can be useful in health promotion and population approaches to mental health. Seligman and Csikszentmihalyi (2000), in an introductory paper on the conceptual framework of positive psychology, fundamentally asked how psychologists can “prevent problems like depression or substance abuse or schizophrenia in young people who are genetically vulnerable or who live in worlds that nurture these problems” (p. 7). They observed that the disease framework of mental health has prevented psychology from focusing on illness prevention. Major strides in the domain of prevention have come mostly in the area of building competency, as opposed to correcting individual deficits. While researchers have recognized that there are human buffers against mental illness such as courage, future-mindedness, optimism, skills, work ethic, hope, and perseverance, the next task is to better understand such virtues and engage people to apply them in real-world settings (Seligman & Csikszentmihalyi, 2000).

Citizenship-oriented care in public mental health settings could function as this next step in the prevention domain. With more inclusive public health approaches, citizenship-oriented care can address various forms of social and health inequities. In this chapter, we describe the citizenship framework’s beginnings in the practice of mental health outreach, focusing on people
who are homeless and persons with mental illness and criminal charges. While our citizenship research to date has largely concerned persons with histories of psychiatric problems, we believe there are lessons to be learned from people with mental illnesses who face adversity and strive to find their way toward, or back to, well-being. For example, a Community-Based Participatory Research (CBPR) project, in which a number of people with mental illness were involved in creating a new measure of citizenship, exemplifies the lessons that can be learned.

**Background**

In the 1990s, Rowe (1999) identified citizenship as a way of thinking about community integration for people who are homeless and mentally ill. Citizenship is defined as a strong connection to the rights, responsibilities, roles, resources, and relationships – the 5 Rs – that society offers to its members through public and social institutions and associational community life. The idea of citizenship also highlights a sense of valued belonging in society that is validated by fellow citizens (Rowe, 2015; Rowe et al., 2012). It became clear, over time, that citizenship had a special relevance to persons with mental illness, particularly those who face criminal justice charges or have been previously incarcerated. Thus, Rowe and Baranoski (2000) introduced the concept of citizenship as a theoretical framework.

Citizenship has since informed the development of programmatic and policy initiatives aimed at the community integration of persons with mental illness and criminal justice histories. Jail Diversion and like programs, researchers argued, can redirect people from criminal to mental health systems. However, movement from one system to another, even if more benign, does not, by itself, support their community integration (Rowe & Baranoski, 2011). In addition, people with mental illness often run afoul of the law, not out of mens rea, but because of behavior directly related to symptoms of their mental illness, their lack of social skills, or the exigencies of poverty, including homelessness. Many times, their “criminal conduct” involves an element of trying to make contact with their fellow citizens and reflects an understanding that doing so is a social expectation they share with others (Rowe, 2015).

How could this citizenship framework be translated into practice to help this group? In one example, a planning group including people in recovery from mental illness and substance abuse (PIRs), clinicians, advocates, and researchers developed a four-month intervention with three components: (1) classes taught by a project director (with advocacy, not clinical, experience), community members, peer mentors, and sometimes participants (students) themselves, on topics ranging from rights and responsibilities of people with mental illness and criminal justice systems, to public speaking and intimate relationships; (2) valued role projects, in which students combined life experience and class learning to “give back” to their community while demonstrating to themselves and others their ability to fulfill socially valued roles, such as teaching police cadets about the experience of having a mental illness and the feeling of being approached by a police officer on the street; and (3) wraparound peer mentor support, in which persons with mental illness and, typically, criminal justice histories, act as guides, counselors, and advocates to students (Rowe et al., 2009). Later, a fourth component, student “What’s Up?” discussions, was added. Such discussions, focused primarily on citizenship and the “whole person,” not the “person with mental illness” or the “ex-convict” (Bellamy, Rowe, Benedict, & Davidson, 2012; Rowe, 2015), were incorporated as a result of the study described immediately below.

A randomized controlled trial was conducted to compare outcomes for participants receiving the citizenship intervention, along with usual public mental health services, to those receiving public mental health services alone. Analysis of baseline, six-, and 12-month interviews showed...
significantly reduced alcohol and drug use and significantly increased quality of life for the citizenship group compared to control group participants. Criminal charges decreased significantly among both intervention and control groups (Clayton, O’Connell, Bellamy, Benedict, & Rowe, 2013; Rowe et al., 2007). From observational inquiry and discussion with student cohorts, we learned that the citizenship group, initially conceived of as a “pass-through” supportive setting to help people move from the margins of their communities toward greater citizenship, became a new sub-community for participants. The group supported their citizenship efforts both in the community and in society at large (Rowe et al., 2009).

**Citizenship measure development**

In previous studies, the authors of this chapter and other colleagues have employed community-based participatory research (CBPR) methods, a capacity-based approach to research and program development that involves persons of primary interest in all aspects of the process. In CBPR, persons who typically are the “subjects” of research have an active role in the conceptualization, implementation, and analysis of studies (Rowe, 2015; Wallerstein & Duran, 2006). Using a CBPR approach, people with mental illness were part of a Co-Research Team (CRT) and discussed the meaning of their contribution to CBPR, emphasizing the ideas of co-learning and acknowledgement of privilege and power. Of symbolic importance was the idea that CRT members would gradually become agents of change in their own communities, conveying a new and more inclusive interpretation of citizenship that would go well beyond a deficit-based definition of mental illness. Thus, we thought that CBPR would be a useful, as well as ethically compelling, research method to support the empowerment (Gutierrez, 1994) and citizenship of people with mental illness, particularly regarding our interest in developing an empirical measure and model of individual citizenship.

Our CBPR approach was to hire and train a group of PIRs as co-researchers in all elements of a concept-mapping study. Potential items for a measure were solicited from the population of focus, followed by reduction of items, ranking and sorting exercises, computerized analysis of domains, and final item selection (Trochim & Kane, 2005) to set the stage for a validation study. We hypothesized that persons who have experienced significant life disruptions or “off-timedness” (Kessler et al., 2005; Pickett, Cook, & Cohler, 1994; Stanton & Revenson, 2006), in which they return to normative society after a period of absence removed from it (as with a first-break psychiatric hospitalization or overseas military duty), will have both common and different experiences of citizenship within and across different disrupted groups as compared to persons without such life disruptions. By testing this hypothesis, we also hoped to identify areas of “citizenship support” for persons with mental illness in general.

We began by generating citizenship items in separate focus groups with persons who: (1) were receiving mental health care, (2) had been incarcerated, (3) had experienced serious medical illnesses, (4) had experience with more than one of these life disruptions, and (5) had not experienced any of these disruptions. Focus groups began with the prompt, “To me, being a citizen means . . . ,” in response to which participants were asked to speak freely and generate as many items as possible. Our five participant groups and six focus groups, with oversampling of “non-disrupted” participants for comparison of disrupted and non-disrupted groups, offered over 700 statements. We condensed these to 100 items, removing duplicates and clarifying the meaning of some statements. Using these items, we then conducted individual concept-mapping sessions. Concept-mapping integrates input from multiple stakeholders, uses sophisticated multivariate data analysis, and creates a series of “maps” or visual representations of data to guide measurement development (Trochim & Kane, 2005). This method has been
used extensively in the psychosocial rehabilitation field (Behar & Ydaker, 2009; Shern, Trochim, & LaComb, 1995), including with mental health service users (Trochim, Dumont, & Campbell, 1993).

In the next stage of the study, persons identifying with one of our five study groups, whether or not they had participated in the focus groups, completed an individual “sorting and ranking” exercise. They were given a list of the 100 citizenship statements and asked to sort them into groups based on similarity. They were then asked to rate each of the 100 statements on a Likert-type scale from 1 (strongly disagree) to 5 (strongly agree) based on the importance of the item to them individually and their sense of their achievement of that item. These groupings and importance ratings were entered into a database and analyzed with a concept-mapping software program (Concept System Software, Ithaca, NY) that compares item categorization across all participants. A high sum for any pair of items indicates that many participants sorted the items into the same grouping, representing a high perception of interrelatedness for these items. The total matrix was analyzed using multi-dimensional scaling analysis (Davison, 1983) and input into hierarchical cluster analysis using an algorithm to place the multi-dimensional scaling into non-overlapping clusters (Everitt, 1980). Item analysis was also conducted to identify items that were rated most/least important and most/least achieved by individuals identified with each stakeholder group.

We found that citizenship is a multi-dimensional construct and that individuals with different life experiences perceive varying degrees of inclusion or involvement in relation to a number of associated activities, social constructs, and values. A 46-item instrument of citizenship was developed through this study (Rowe et al., 2012) and later validated with participants receiving care at a public mental health center (O’Connell, Clayton, & Rowe, 2016; Pelletier et al., 2015).

While the purpose of our study was to develop an instrument to measure the citizenship status of persons with mental illnesses, with the ultimate goal of supporting their achievement of full citizenship through citizenship-informed supports and interventions, we were also interested in the experience of our co-researchers’ participation in developing the measure. We conducted a focus group with PIR co-researchers. PIR co-researchers were asked three questions about their experience: “What was your role?”, “What did participating mean to you?”, and “What was your contribution to the study?” We identified five major themes from their comments: (1) experience as research partners, (2) change in status and changing others, (3) learning new skills, (4) feeling respected and validated, and (5) being paid. In the remainder of this chapter, we examine each theme and its contribution to the idea of citizenship.

### 1 Experience as research partners

Co-researchers (CRs) generally felt fully involved from the beginning and supported by faculty researchers through formal and informal training and support. “When we go through our own battles, they are there supporting us,” said one CR. Most said they would not have applied for the position without previous contact with faculty who encouraged them to join the team. Most already knew at least one of the faculty researchers from being participants in previous studies or in their recovery journeys. “If I saw that in the paper I would think automatically that I don’t qualify,” said one. CRs’ welcoming approach to study participants, observed by faculty researchers, may have been encouraged by the support they received in their new roles. “We are all in this together,” said one CR of study participants.

CRs’ role in the project was well defined. They were trained (and paid) to conduct focus groups, concept-mapping sessions, and to participate in item reduction and final item selection. But there was also an implicit and informal role for them simply by virtue of being research team members – the research involved the topics and concepts of social inclusion and
citizenship, not disease management or prevention. The formal objectives of the project and its vocabulary were consistent with their roles and with a recovery perspective. To several who had been out of the labor market for extended periods or whose work did not carry high or valued role status, being a respected team member had special meaning:

I just felt like, I just can’t believe that doctors would want us on their team and be equal. I felt overwhelmed, felt joy to be sitting next to them equally knowing that they have all that education, went to school all that time. I did go to college but I don’t have what they have and still [here I am] on the same page. I felt very . . . I felt amazed.

CRs were selected in part for their anticipated ability to help research participants feel respected, valued, and at ease. As one CR member explained:

I made sure that before we started, that they were comfortable. And they could see me, that I was comfortable, the way I was dressed and the way I moved, the way I talked. They know this lady is from “the hood.”

CRs also felt, or heard later on from research participants, some of whom they knew personally, that their participation had a ripple effect extending back to their (research participants’) communities:

The people that were doing the focus group, they even took what they got . . . back to their community. You know what I mean, like a lot of stuff they felt was wrong in their community they hollered out the statements, but after listening to the statements . . . they went home and it was a change for them.

CRs also felt that there was an “outreach” component to their participation as researchers:

When I came here for the research, when I first entered and sat down, I said, “Well, is this what we’re going to be doing, talking at the table like this?” They said “Yep.” I said, “We’re not going into the community?” “No.” I said to one of the researchers, “I don’t think I’m coming back because I’m used to going out.” I didn’t want to be sitting here and listening to them and me talking. I like to be hands-on. So that first day I wasn’t going to come back but after I heard what was going on, I said maybe this won’t be bad, maybe I don’t have to be hands-on with somebody. So I said, “OK, I’ll come back the next time and see how it goes.”

2 Change in status and changing others

CRs saw themselves as agents of change not only in their own communities, but also in the “research community.” One commented, for example, on faculty researchers’ focus on the CBPR process itself: “It feels like it’s more of the gut of the change.” Another said:

They look at the “what’s next” as well. They may not have gone through the same life experiences [but] . . . I’m getting there, an equal to the folks here that I’ve met.

CRs also noted their roles in explaining to research participants the purpose of the study and the orientation of the citizenship framework. Some study participants, for example, asked how
the information gained from the focus groups would be used and why they should offer to help. CRs promised that the information was going to be used for positive change:

We’re all doing it together. Even though they gave us the feedback that we were asking for, they’re still a part of the rest of the cycle of where this is going to head to... Let’s say if a clinician told me [I would remain involved in] the next steps [after participation in the study], I wouldn’t believe him. I would think that they were taking all the information and doing whatever they needed to do with it. That’s how I would take it. I think by us being people with lived experiences it kind of like validated to them, yes, you’re going to be involved in this next step and this is going to come to something. Like your information isn’t just worthless, we are not going to just put it in a shelf somewhere.

Being an agent of positive change and learning to cope with change was also part of a series of new qualities and skills that CRT members were able to develop in their training and in performing their tasks.

3 Learning new skills

CRs developed new skills as a result of coordinating the focus groups. For example, a critical challenge in conducting the focus groups on a topic of such interest to CRs was to avoid the temptation of becoming focus group members themselves. Further, CRs had to learn how to insert personal comments that would divert or “taint” the focus group process. As one said:

There were also parts that were very emotional... It touches a piece of your life that might have been painful.

Faculty researchers guided CRs on standing back and balancing their passion to ensure that the focus groups and item development would truly reflect what participants had in mind.

Faculty researchers had also noted that conducting focus groups in which participants were invited to speak freely seemed to lead CRs, at times, to revisit difficult periods in their lives. They asked them about this in the CR focus group, but were told that while this did happen for them, it was not “too hard.” On the contrary, the experience of having difficulties and obstacles in life, and of revisiting them, in the words of one, was “character building. And it makes one more compassionate towards others. And it’s a tighter bond [with them].”

Being valued and recognized as CRs, with their vulnerabilities and strengths, seemed to show them, and others, that they “can get things done” and that they are “competent and effective.” This capacity, some noted, was not something they possessed “in spite” of their mental illness, but was something they had discovered in their recovery journeys that gave them the insight for and interest in helping others. For example, one member said, “It’s like expanding on what I’ve already done. You know, taking that next step, the next level and seeing how that part works.”

However, this is not to say that participation as a CR was without its difficulties. Said one:

I didn’t think I was going to get it. And I just kept coming and doing it and I was even able to help somebody else. I didn’t know a lot but I know a lot more now, about a lot more stuff.

Among other benefits, CRs reported being able to get letters of reference and to have a stronger resume with newly acquired skills and responsibilities. They also revealed that they were able to look back with pride at what they had accomplished for themselves and others.
4 Feeling respected and validated

Aside from formally acquiring new skills and relational abilities, CRs were exposed to work in which they felt respected and validated. When asked about the formal training they had received, they tended not to recall the specific details of the training or describe it as discrete learning experiences. Instead, they commented on the validation of the training and research participation, emphasizing the inclusion and solidarity they felt with faculty and program staff:

It’s not just sitting and being in the same setting, it’s having this special role. We are validated. They took what we said and used it and we were being heard even though they have all that education. It wasn’t me just sitting next to them, it was when I spoke they listened and then validated what I said.

CRs are able to contribute to research and to the development and maintenance of an especially inclusive and positive culture. One member characterized the research environment as a functional, meaningful workplace:

I can be part of the table. I do have some assets that are valuable at somebody’s agency. That helped me, because I’m a person in recovery from addiction so I have this low self-esteem and no sense of belonging, so like the way it all happened was like wow! They helped to build my own stamina up, you know, like accomplishments, true friendships … not working those little $8.25 an hour jobs where you are just another number.

Having dealt with judgmental or dismissive attitudes from some mental health professionals in the past, CRs were sensitive to the importance of not being judgmental toward study participants:

There was also an effect on the people we didn’t know, ’cause they saw that we were warm and friendly and approachable, which I think made it easier for them too . . . I can change some roles, OK?

In addition, CRs felt that they serve as role models and as providers of hope to participants:

I think that us, from going through some stuff, and them seeing that too, gives them a mind frame that “I could do the same thing.” You know what I mean, like “If they can do it I can do it.”

5 Having income

CRs appeared to experience their participation as both meaningful and personally transformative. They were also paid for their contributions:

It’s not, “Oh, you’re going to get a $50 stipend.” . . . For the things that I have done, I’m truly a part of this organization. And I would come without the pay to tell you the truth.

In spite of the final-sentence disclaimer above, CRs said that being paid “helps a lot.” It also symbolizes the fact “that you are valued . . . that your input and contribution is valued.”
the money they were paid was not substantial, it allowed them to treat themselves and their loved ones to something extra:

There is a lot of poor folks in this economy, go to work every day – “Here’s your paycheck,” – and you just gotta pay your bills . . . One of the things that I was able to do, was do something nice for me. Or for my kids, buy a little extra, you know ’cause it wasn’t that counted-on, that budgeted-out money that I have to do. You know I’m still struggling and stuff but I worked for this. It’s a little bit extra that I may count on.

At times and for some, the money they received made a critical difference in their lives. “It helped, it helped our families,” said one. “I was able to go home and feed them.”

Discussion

The engagement of CRs in a community-based participatory research project on citizenship can be seen in light of the themes of positive psychology. Seligman and Csikszentmihalyi (2000) argued that “psychology should be able to help document . . . what policies result in the strongest civic engagement” and that, at the collective level, “the field of positive psychology . . . is about the civic virtues and the institutions that move individuals toward better citizenship: responsibility, nurturance, altruism, civility, moderation, tolerance, and work ethic” (p. 5). Both positive psychology and our citizenship framework aim to support people’s access to and engagement in a meaningful life (Seligman et al., 2005). Kobau et al. (2011) suggested ways of articulating positive psychology and health promotion. In our common efforts to take what we “have learned about the science and practice of treating mental illness and use it to create a practice of making people lastingly happier” (Seligman, Steen, Park, & Peterson, 2005, p. 410), we propose to further move away from a disease framework by using the citizenship framework as a form of health promotion (Breslow, 1999).

To improve the mental and physical health of populations, the WHO has since 2003 advocated for moving mental health from the periphery of health policies and practices to a more prominent position in the field of global public health (World Health Organization, 2003). Eighty years ago, the British Medical Journal reported an association between mental illness and poor physical health (Philips, 1937). Subsequent research in many countries has confirmed that psychiatric patients have high rates of physical illness, much of which goes undetected (Giddings, 2013). Because how one thinks and feels has a strong impact on one’s physical health, there is truly “no health without mental health” (Prince et al., 2007; Jane-Llopis & Mittelmark, 2005). This suggests the need for more health promotion activities for psychiatric patients (Phelan, Stradins, & Morrison, 2001). In principle, individuals who live with psychiatric disabilities have the same rights as anyone else to a healthy life and to health care. At the same time and complementarily, “happy people are healthier, more successful, and more socially engaged” (Seligman et al., 2005).

The year 2016 marked the 30th anniversary of the Ottawa Charter for Health Promotion, adopted at the First WHO International Conference on Health Promotion (World Health Organization, 1986). The Ottawa Charter established the fundamental guiding principles and values of health promotion as a practice. They proposed five strategic action areas to address social determinants of health, which has inspired clinicians, social workers, teachers, academics, and policymakers, among others, and has catalyzed research on well-being (Eiroa-Orosa, Chapter 23 in this volume). The strategic action areas include: Build healthy public policies, create supportive environments, strengthen community actions, develop personal skills, and reorient
health services. In the remainder of this discussion, we articulate the five Rs of our citizenship framework – rights, relationships, roles, responsibilities, resources – in relation to the five action strategies of the Ottawa Charter for Health Promotion.

**Build healthy public policies and Rights**: Both health promotion and citizenship go beyond healthcare stakeholders to influence the agenda of policymakers in all sectors and at all levels (Ottawa Charter). They seek to put health and health equity at the forefront of electoral debates through a collective sense of responsibility based on human rights. Such a population approach may pave the way to greater access to public resources and social inclusion, not only for people with mental health difficulties, but also for everyone.

**Create supportive environments and Relationships**: Changing patterns of life, work, and leisure have a significant impact on health, mental health, and happiness (Ottawa Charter). Creating supportive environments is equally essential to health promotion and to full citizenship. Physical and social environments can generate isolation and thus affect the ability of marginalized people and communities to cope with physical and mental health issues. Isolation may result in a lack of social networks and diminished social capital, which can contribute to obesity, cardiovascular disease, mental health problems, and increased rates of mortality (Srinivasan, O’Fallon & Dearcy, 2003).

**Strengthen community actions and Roles**: Communities can enhance self-help and social support and develop flexible systems for strengthening public participation on matters of health (Ottawa Charter) by acting upon the specific mechanisms of their environment. Communities can make their environments safer, more stimulating, more satisfying, and more enjoyable. They can also boost awareness of their impact on both physical and mental health. In communities oriented toward citizenship, mental health service users can play stronger roles in developing, planning, and implementing such policies and services (Bradstreet & Connor, 2005). Individuals and communities ought to be able to identify and realize their aspirations, satisfy their needs, and change or cope with their social environment. Similarly, citizenship is a measure of the extent to which individuals can carry out their aims and satisfy their basic needs to evolve and take an active part in respective communities.

**Develop personal skills and Responsibilities**: In order to recover, one has to be able to practice and exercise empowerment and agency (Green, Poland, & Rootman, 2000). Agency requires a certain level of mental health (Bandura, 1999). It is critical for communities, systems of care, and governments to act simultaneously to support healthy lifestyles for individuals. On a larger scale, they must also support environmental settings in which social norms support hope, especially for those with chronic illnesses. Engaging and enabling people to learn about and prepare for all life stages and to cope with chronic illness and injuries is essential. This must be facilitated in school, home, work, and community settings (Ottawa Charter). The four components of our citizenship model converge to support students in the exercise of new responsibilities and the development of personal skills to maintain them.

**Reorient health services and Resources**: The Ottawa Charter states that

> The role of the health sector must move increasingly in a health promotion direction, beyond its responsibility for providing clinical and curative services... This must lead to a change of attitude and organization of health services which refocuses on the total needs of the individual as a whole person.

*(World Health Organization, 1986, p. 3)*

Similarly, a citizenship-oriented system would allocate some resources to support positive social inclusion among marginalized people with special needs and challenges, not merely access to care. As social capital is a predictor of both health and mental health, a citizenship-oriented
intervention would build on their lived experience of exclusion to promote community cohesion. For instance, peer mentors could support people with mental illnesses by identifying and using community resources.

Conclusion

Having access to appropriate health (including mental health) care when needed is a human right (Kinney, 2000). The idea that patients can have a say over the manner in which care is provided, including partnership in the decision-making process, has gained increasing support among recipients and providers of care. Yet many people need to be supported in recognizing and expressing their needs, opinions, and expectations regarding their health care. As positive psychology seeks to increase individual happiness with efficient psychological interventions, it might be appropriate to recall, as Aristotle wrote about 2,300 years ago, that human happiness is the fulfillment of human beings in the life of the city (or society, as we would say at present). Humankind is only fully realized in a democratic political regime through the expression of citizenship in light of collective happiness. We thus need to know what it means to be full citizens in order to help people regain their citizenship who have been socially and economically marginalized due to mental illness. Offering such opportunities through research as an inclusive sub-community can be a pivotal factor in this effort.

References


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