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A Theory of Social Integration as Quality of Life

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Abstract

Objective—Quality of life, once a priority in caring for people with severe mental illness, has since been eclipsed by other concerns. This article returns attention to quality of life by offering a theory of social integration (as quality of life) for persons disabled by severe mental illness.

Methods—Data collection for this qualitative study consisted of 78 individual, unstructured interviews with 56 adults who have been psychiatrically disabled and field observations and interviews with staff and users that were made during eight ethnographic visits to service sites working to promote social integration. Data were analyzed with an inductive strategy based on grounded theory methodology and framed theoretically by the capabilities approach to human development. Goals were to identify personal capacities needed for integration, characterize occasions for capacity development in mental health care, and develop a working theory.

Results—Six personal capacities were identified: responsibility, accountability, imagination, empathy, judgment, and advocacy. Occasions were characterized in terms of their defining mechanisms: contradiction, reinterpretation, rehearsal, raising expectations, and confrontation. A working theory was constructed to characterize the process of capacity development for social integration through exposure to increasingly challenging occasions for growth in the context of mental health care.

Conclusions—Capacities for social integration can be effectively developed as part of the everyday routines of mental health care. Eventually, the process shifts from development to the exercise of capacities and to participation as full citizens in the social world beyond treatment.

The idea that mental health treatment should result in a better life for persons with severe mental illness dates back to at least the 1970s, when improvement in quality of life was declared to be the goal of the National Institute of Mental Health's Community Support Program initiative (1,2). For a time, quality of life attracted considerable attention (3–7). Then other pressing concerns intervened (8).

In the 1980s, the presence of persons with severe mental illness on the streets and in homeless shelters occasioned a crisis requiring a response (9–13). Later, the movement for mental health system reform brought another shift in priorities. With managed care came demands for cost-effectiveness (14), measurable outcomes (15), and evidence-based standards for the treatment

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of severe mental illness (16,17). The emphasis on quality of life has been largely eclipsed as a result.

This article returns attention to this topic, raising questions about what quality of life in the context of severe mental illness should mean as both an outcome of treatment and an object of research. We aim to reformulate the concept in a way that sets higher standards, reflects the new emphasis on recovery, and construes quality of life not as well-being but rather as agency (18–23). Social integration serves as our substantive focus. We define social integration as a process through which individuals with psychiatric disabilities develop and increasingly exercise capacities for interpersonal connectedness and citizenship (24).

A capabilities approach to quality of life

The capabilities approach to human development provides the conceptual framework for this exercise. The product of decades of scholarship in development economics and moral philosophy (25–29), the capabilities approach reconceptualizes quality of life for disadvantaged populations (30). It was developed as an alternative to utilitarian formulations that use personal satisfaction and income as primary quality-of-life indicators. Until recently, the capabilities approach has been associated principally with the study of standards of living for poor people in developing countries. We are now seeing it put to other uses, including rethinking disability and disparities in health (31–35). All of these efforts target social structures outside service systems.

Our goal here, in contrast, is to use this set of ideas to construct an individual-level theory that can guide efforts to foster social integration for persons with psychiatric disabilities receiving mental health care. From a capabilities perspective, quality of life is construed in terms of agency, that is, intentional, self-directed action. Realization of agency is dependent upon the synergistic combination of two essential ingredients: personal capacity and social opportunity.

Personal capacity refers to attributes of individuals that equip them to exercise agency. Capacities are both inherent and developed, meaning that a certain amount of capacity may “come naturally.” Inherent capacities improve and new ones are acquired with learning and practice. Personal capacities constitute “agency potential.”

Capacities are not the same as skills. Though both suggest competence, we may think of skills as competencies acquired through practice, such as playing the piano or—in the context of mental health treatment—symptom management, emotion regulation, or stress reduction (36–38). Capacities, in contrast, are competencies acquired through developmental processes aimed at moral, social, cognitive, and emotional growth. Skills may be thought of as performative and capacities as generative.

Opportunities are real options for action in the social world outside service systems. To take advantage of opportunities, individuals must have both the requisite personal capacities and the needed resources. Reading, for example, requires both literacy (capacity) and reading material (resource). The ability to take advantage of opportunities is mediated by circumstances of the social environment—social processes (for example, discrimination), laws, customs, and policies. Real opportunities enable an individual to pursue socially valued ends. Both the pursuit and the achievement of these ends improve quality of life. In what follows, we use the term “occasion” to refer to opportunities occurring as part of mental health care.

The research

This article is the second in a planned series of reports from an anthropologically informed, qualitative study. The study used the capabilities approach to define social integration in the

context of psychiatric disability and build a theory that explains how capacity development for social integration may take place. Data were collected from 2003 to 2005. The first report from the study offered a new definition of social integration (see above) (24). Here, we address the study's second, theory-building objective.

Methods

Data collection

Two types of data collection activities were carried out for this study: individual in-depth interviews and brief ethnographic visits. In-depth interviews were conducted with adults who had been psychiatrically disabled but who, in the judgment of the investigators, had become more socially integrated since disablement. Judgments were based upon information forwarded by service providers and made collectively by the research team. Interviews were unstructured and worked to elicit detailed accounts of experiences related to social integration. Seventy-eight interviews were conducted with 56 interviewees.

Brief ethnographic visits were short stays at service sites that work to foster social integration for persons with psychiatric disabilities. The purpose of the visits was to understand how this takes place. Eight visits were made to five programs: a psychiatric rehabilitation facility, a consumer-run drop-in center, a therapeutic community, a residential and employment program aimed at "redefining community," and a community-based treatment center for young adults with psychosis. Visits lasted for one to two days and included interviews with staff and program users and field observations.

The study was approved by the Committee on Human Studies at the Harvard Medical School and by the Institutional Review Board at the Nathan S. Kline Institute for Psychiatric Research. Informed consent was obtained from all study participants with an approved consent form.

Data analysis

Strategies for analyzing qualitative data are not simply pulled "off the shelf" but rather custom-built to fit each investigation (39,40). To construct a theory showing how capacities for social integration may develop for individuals with psychiatric disabilities, we used a theory-driven-but-inductive approach to data analysis informed by the capabilities approach. The observational and interview data were analyzed—first, to specify the capacity construct and second, to characterize occasions for capacity building in mental health care.

We posed two analytical questions: What capacities are needed for connectedness and citizenship? and What do occasions for building capacities that foster connectedness and citizenship look like? To address these questions, interview transcripts and materials derived from observations (notes on ethnographic visits, notes on investigator discussions of ethnographic visits, and transcripts and recordings of interviews conducted during visits) were reviewed and discussed in face-to-face, day-long meetings of the research team and in telephone conferences. Twenty-three such meetings and conferences took place over two and a half years.

To identify capacities needed for social integration, the team selected from the larger corpus of data sections of text that they judged to represent instances of connectedness and citizenship. We then characterized the capacities involved by naming and defining them in ways intended to reflect both the meanings inherent in the text (in contrast, for example, to dictionary definitions) and insights and understandings developed in the course of conducting the research. This analytic strategy is informed by the grounded theory approach to qualitative data analysis (41–43).

Much the same procedure was used to characterize occasions for capacity building. Sections of text that represented interpersonal interactions between individual providers and recipients of mental health care and that were judged to exemplify an occasion were identified, named, contextualized, and interpreted by the team. Names were selected to represent the change processes that defined each interaction as an occasion. This means that occasions are represented as mechanisms of change.

Once instances of capacities and occasions had been fleshed out, a hypothetical process specifying how they interact, informed by the capabilities approach, was formulated. The statement of this process is the promised working theory of capacity building for social integration.

Results

Presentation of study results reflects the theoretically informed, yet inductive analytical process described above. We show how the analytical questions intended to specify capacities and occasions were answered, and we lay out the theory of capacity development for social integration.

To answer the analytical questions, six capacities and five types of occasions were identified. Capacities are moral, social, cognitive, and emotional competencies that build maturity and anchor social action. Occasions are represented as change mechanisms fostering capacity development. An overview appears in Figure 1.

What capacities are needed for connectedness and citizenship?

The following capacities are suggested by the data.

- Responsibility is the ability to act in ways that reflect consideration and respect for others.
- Accountability is being answerable to others for the consequences of one's actions in the context of a given set of social or moral standards.
- Imagination is the ability to form ideas and images in the mind and know they are mental creations.
- Empathy is the ability to envision, understand, or identify with others' points of view.
- Judgment is the ability to form sound opinions and sensible decisions in the absence of complete information.
- Advocacy is the ability to argue articulately for a position orally or in writing.

The relative salience of social, emotional, cognitive, and moral dimensions varies across capacities. Empathy, for example, is prominently social and emotional. Cognitive and emotional dimensions are especially salient in advocacy. In responsibility and accountability, social and moral dimensions come most quickly to the fore. A major advantage of the capacity construct and the larger capabilities approach is that they highlight the moral dimension of agency, thus allowing moral experience, or "what really matters" (44), to be introduced into the discourses on social integration following psychiatric disability and the meaning of recovery from mental illness.

What do occasions for building capacities look like?

To address this question, five types of occasions were identified. Occasions are defined as structured mechanisms of change leading to capacity development. Here, mechanisms of change are embedded in microexchanges between mental health providers and users of care.

In each type of occasion, change is directed at building capacity for connectedness or citizenship. The five types of occasions represented—contradiction, reinterpretation, rehearsal, raising expectations, and confrontation—are those most salient in the study data.

Contradiction—Mr. M, an interviewee, described being evicted from a homeless shelter because of repeated rule infractions. He was angry about the eviction. However, his anger was tempered-and complicated-by the fact that although shelter staff had instigated the move, they had also found him a new placement, helped him pack his things, and driven him to his new residence. Mr. M was impressed but also confused: “I couldn’t just call them jerks!” he exclaimed. “True, they kicked me out, but look what they also did for me!” This seemingly contradictory juxtaposition of callousness and concern triggered a shift in both perspective and behavior for M. “I remember it really clearly,” he said. “I got to the new place, and when I walked through the door I said to myself, ‘This is my chance to do things differently.’ And I did. It started there. I started being accountable to people.”

Reinterpretation—Reinterpretation is occasioned by encounters with new meanings of a familiar idea. In the following interview excerpt, Ms. S recounts an experience of being asked to “call in” to the halfway house where she was staying. In the course of the interaction, she encounters a new meaning of “call in.” Though calling in was previously experienced as an infringement on her independence, in the interaction depicted below Ms. S is presented with the fact that calling in can also signify consideration for others. Learning and acting on this new meaning, Ms. S subsequently becomes more “responsible.”

“I remember the first time they asked me to call in when I went somewhere. It was like, ‘Call in? You ain’t my mother! I ain’t callin’ you. It’s my business where I go and what I do!’ And she [staff person] was like, ‘But we worry about you!’ And I said, ‘Nobody worries about me, so don’t even go there. I’m just here for a place to live until I can get through school and get my own apartment.’ And she was like, ‘Well if that’s all you’re doing here, you could go back and sit on a ward and do that.’ And I was like, ‘Wait a minute, what do you mean?’”

Rehearsal—Enactment is essential to capacity. Hence a third capacity-building mechanism is rehearsal. By rehearsal, we mean executing a developing capacity in a learning environment, with the expectation of feedback. The psychiatric rehabilitation program participating in this study enables participants to rehearse being students by using an adult education model of practice. The community-based psychosis treatment center organizes theater workshops led by professional actors who stage rehearsals of emotional and imaginative capacities—empathy in the form of adopting multiple perspectives on a situation, for example. By creating a “living-learning” environment for the practice of reciprocal relationships, the therapeutic community we visited functions continuously as a “rehearsal stage” for connectedness and citizenship in the larger social world (Dickey B, Ware NC, unpublished manuscript). Rehearsal may usefully be contrasted with practice, cited above as a means of skill development. As a capacity-building mechanism, rehearsing creates experience.

Raising expectations—In a fourth example, we see increased sociability brought about through a subtle raising of expectations. During a study interview, Mr. R referred to a “turning point” after which he became more open to connecting with others. As Mr. R described it, conditions for the change were created by Ms. T, a mental health practitioner who was consistently respectful and “nice” to Mr. R. When he returned her greetings with “go to hell,” she simply smiled. When he hung up on her telephone calls, she proceeded as if nothing had happened, inquiring after his well-being as usual. Then, one day, Ms. T’s congeniality cooled. “She stopped talking to me,” Mr. R reported. “She stopped saying ‘hi,’ asking me how I was doing.” Mr. R found he missed the “attention.” The pull of the connection he had come to expect outweighed the urge to remain interpersonally distant. Tentatively, he “tested the

waters,” as he put it—initiating greetings, being the first to “say hi.” “And that’s how it started,” Mr. R concluded. “Little by little. Talking. Then the conversations started getting longer and longer. Next thing you know, I was in her therapy groups.”

By exhibiting warmth and respect, Ms. T modeled an alternative to Mr. R’s characteristic rudeness and expressions of anger. By pulling back at a certain point, she signaled that his usual demeanor was no longer acceptable, in effect “changing the rules” of interaction between them and setting a higher standard. The new standard required that respect be warranted or “earned” through socially acceptable behavior. Mr. R promptly responded, becoming more considerate and respectful—“nicer”—and more connected to others.

Confrontation—The last mechanism we term “confrontation.” By confrontation we mean deliberate challenges to actions that fail to meet accepted standards. Confronting unacceptable actions on the part of individuals with severe mental illness sets an expectation of accountability. It assumes capacity, reinforces connectedness, and communicates that how one acts affects others—that in social interactions, something real is at stake. This is aptly illustrated in the following interview excerpt, in which a staff person at the participating therapeutic community describes her response to a resident who “faked” an injury to escape work responsibilities.

“My first thought was I want him punished. But because I felt that way I realized the worst thing I could do was talk to him at the time. So I wrote him a note about how it felt to be lied to, and how it felt to realize that he was a dishonest person, and that our trust was broken, and that that was going to have lasting consequences. The consequences that arise from people’s actions are natural, and as a natural consequence of his lying to people, I’m not gonna trust him. And that’s going to be really hard for us to work around.”

Not every capacity-building occasion produces immediate change, as the remainder of this anecdote makes clear. The staff person’s attempt to communicate a lesson in the interpersonal consequences of dishonesty initially went unheeded—her note was interpreted and dismissed as simply a “list of complaints.” Subsequent attempts, at least one of which involved third-party mediation, led to an understanding of the grievance (note: a form of empathy) on the part of the resident. Eventually, the relationship was, if not strengthened, at least returned to its original state.

A theory of capacity building for social integration

Having laid out the constituent elements of the theory—capacity, occasion, mechanism—we come now to the task of stating them as a proposition, as follows:

Individuals with psychiatric disabilities bring preexisting capacities to the development process. Existing capacities expand, and new ones take root, through exposure to occasions for growth. Occasions present challenges and may be simple or complex, that is, made up either of single interactions or of orchestrated sequences arranged in order of increasing difficulty. As challenges are mastered via mechanisms—contradiction, reinterpretation, and so forth—competency is affirmed, a sense of possibility emerges, and with it, aspiration. Together, aspiration and a sense of possibility fuel engagement with new, more challenging occasions. Capacity builds and expands into agency in an iterative, open-ended process.

This process is depicted schematically in Figure 2.

Occasions for capacity development share a number of characteristics. They assume that capacity development is possible and will take place. Practitioners act accordingly by setting expectations for performance and insisting that the expectations be met. They also allow for

the possibility of failure and, when it occurs, find constructive ways of responding. Constructive responses examine failure and place it in perspective but also allow the consequences to unfold. Genuine actions and events are characterized by the fact that something significant is at stake.

The development process is expected to be neither uniform across capacities nor steady in pace. Slippage, stalling, and temporary reversals will occur. Unexpected obstacles will crop up. Challenges will be declined. An adequate theory must account for such contingencies, as the representation we offer attempts to do.

Discussion

Our intent has been to construct a working theory of capacity development for social integration that applies to persons who have been psychiatrically disabled. The theory reflects the capabilities approach. The capabilities approach offers several advantages as a conceptual framework. It assumes diversity and treats growth rather than chronicity as a way of thinking about life possibilities following psychiatric disability. Growth is the contingent outcome of a dialectic between the individual and the social context. The development process is thus one in which occasions for growth follow and build upon one another in order of increasing difficulty. Success and failure, trial and error, are expected parts of the process. Finally, the capabilities approach leads to a framing of quality of life following psychiatric disability that prioritizes capacity for reflective action over satisfaction and functioning.

The working theory posits a spiral-like growth process through which once-disabled persons increase social integration through capacity development. We envision the theory as applicable not only to social integration but also to other aspects of quality of life. We expect it to prove useful in thinking about social integration for persons with nonpsychiatric disabilities and other forms of disadvantage. We hope it will serve as a useful starting point for future empirical research and practice.

Social integration following psychiatric disability may be an ideal goal, but substantial progress in that direction is not out of reach. Field research for this project revealed a number of systematic and innovative approaches to addressing connectedness and citizenship as goals of care. Supported employment programs have placed individuals with psychiatric disabilities in competitive jobs with demonstrated success (45–49). In Europe, intensified campaigns for “social inclusion” have reduced barriers to full social participation for persons with psychiatric disabilities—by affirming rights, addressing public fears, correcting misinformation, and overcoming work-place obstacles (50,51).

Evidence accumulating as part of the “renaissance” in social psychiatry research (52) points to environmental factors as antecedents of psychosis. Migration, discrimination, urban upbringing, and early childhood trauma have all recently been implicated as risk factors for psychotic disorders in epidemiological research (53–60). The positing of causal mechanisms capable of explaining statistical associations adds depth to this area of inquiry and promises further progress in understanding psychosis (61,62).

The working theory outlined here resonates with the social psychiatry “renaissance.” However, it shifts the emphasis from origins to consequences of illness. The fundamental question we address is What kind of life should individuals who have been psychiatrically disabled reasonably be entitled to expect? Social integration in the form of interpersonal connectedness and active citizenship should be a reasonable expectation, we argue, but as a means to a larger end. The ultimate advantage of using the capabilities approach to rethink the consequences of disability is that it leads us to define quality of life in terms of agency rather than well-being

alone. From a capabilities perspective, social integration improves quality of life by equipping people for deliberate action and reflective choice.

Conclusions

A number of questions remain to be answered as this initiative moves forward. What other capacities contribute to social integration besides those we have discussed? How should “occasions” be further specified? How can occasions be linked to opportunities outside the domain of mental health care? And finally, how can the concepts and processes outlined here be operationalized and measured to allow us to both test the theory and begin to put it into practice? Implementation of these ideas is an important next step.

The data presented here demonstrate that capacities for social integration can be effectively developed as part of everyday routines of mental health care. Providers tell us that they find the theory useful as an analytical framework for critiquing their own work. In the future, we expect it to inform the design of interventions aimed at increasing agency as part of recovery from severe mental illness—for example, shared decision making in medication management (63). At some point, the process of assisting individuals in agency development will require coordination of mental health and other service sectors. However, the process must ultimately involve a shift from development to exercise of capacities if recovery is to mean participation as full citizens in the social world outside mental health care.

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Figure 1.
Capacities and occasions for the development of agency and social integration

Figure 2.
The process of capacity development through exposure to occasions for growth