A Seat At The Table: Trend Or Illusion?

The mental health care system needs to pay more than lip service to the notion of consumer empowerment.

by Robert Bernstein

ABSTRACT: Responding to Nancy Tomes’s conclusion that mental health consumers are beneficiaries but not primary causes of a new attentiveness to consumers’ concerns, this review finds various historical and contemporary reasons for the mental health consumer movement to remain vigilant: the system’s shallow acceptance of consumer self-determination; continued reliance on expedient coercive tactics rather than therapeutic engagement; the currently narrow reach of initiatives in self-direction; and the fragmentation of authority in the delivery of public services and supports needed by mental health consumers.

Nancy Tomes’s thoughtful examination of the mental health consumer movement describes the often tumultuous relationship between people diagnosed with a mental illness and the public systems charged with serving them. She concludes that today’s attentiveness to mental health consumers’ perspectives is more a reflection of broader trends than a direct product of the movement’s influence. Political and fiscal pressures, coupled with generalized dysfunction in public mental health, may be primary determinants of what traction the consumer movement now enjoys. As Tomes notes, the consumer presence on planning councils and committees evidences some level of behavior change in the system. But whether what one sees is what one gets remains an open question. If, indeed, this newfound access is not traceable to years of diligent consumer advocacy and, instead, represents a fortuitous alignment of political and structural issues—most ultimately traceable to fiscal containment—there might be good reason for the movement to remain vigilant.

Shallow acceptance of consumer empowerment. First, it is important to recognize the irony when systems ostensibly dedicated to mental health so belatedly, inadvertently, and, perhaps, grudgingly accept the inclusion and empowerment of consumers. In the parallel world of physical health care, consumer empowerment is a good new business model—encouraging, for instance, a healthy lifestyle or a sense of shared responsibility for skyrocketing medical costs. Certainly, these aims can apply to mental health, but here the meaning of empowerment runs far deeper and carries a much longer history. In contrast to conceptualizations of physical wellness, influence over one’s world has long been considered a core element—even definitional—of healthy psychological functioning. Accordingly, in mental health circles, consumer empowerment should rightfully stand not only as an approach to prudent service delivery, but also as an important clinical hallmark. This, of course, has not been the reality, particularly for people..

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in public mental health systems. Judi Chamberlin's writings from almost thirty years ago attest to the emergence of the consumer movement largely as a reaction against practices endemic to these systems that not only failed to promote a sense of empowerment, but actively fostered feelings of hopelessness and incompetence. In sum, the consumer movement can be regarded both as a consequence of oppressive, dehumanizing practices and as a psychologically healthy affirmation of personal and collective influence.

■ **Coercive tactics versus therapeutic engagement.** The relevance of this perspective is far from metaphorical. Instead of acknowledging these inconsistencies and embracing consumer engagement, as Tomes describes, the psychiatric establishment has historically marginalized mental health consumerism as iconoclastic, misguided, naïve, or irrelevant. Translated to the individual level, the system has been prone to pejoratively labeling assertive consumers who do not acquiesce to professional directives as manipulative, noncompliant, or lacking in insight. Notwithstanding prominent statements on Web sites of state mental health agencies professing commitment to consumer self-determination and policy directives for “consumer-centered” approaches, practices that dismiss consumer empowerment remain widespread. For instance, coercive tactics continue to enable providers to deal with consumers expeditiously, rather than therapeutically.

Even outside of these realities, there are essential questions as to whether empowerment can be administratively granted and whether top-down prescriptive policy measures hold any potential for genuinely shifting distributions of power. Although mental health systems publish consumer-friendly language and have been quite self-critical, there has not been a fundamental change in their approaches and interactions with individual users. Some researchers have called for a complete overhaul of mental health care, whereby basic values reflecting consumers’ needs and wishes become paramount, supplanting sterile fixations with clinical effectiveness. Such an epiphany has not occurred and does not appear near at hand. In fact, there is a strong push toward injecting “evidence-based” practices into mental health care. This is not in itself a bad thing, but applied research is not divorced from underlying values, and the preponderance of inquiry in mental health reflects a pharmaceutical, rather than a consumerist, mindset.

So, notwithstanding the system’s current rhetoric and hospitable gestures toward consumerism, some critical bona fides might be lacking. This is not to belittle the system’s long-overdue openness to consumer engagement, but rather to acknowledge that the consumer movement may legitimately reserve some skepticism about the whole enterprise. It remains to be seen if the system’s welcome extends to dissonant consumers and opportunities for meaningful, enduring influence.

■ **Current self-direction initiatives.** Tomes refers to a seemingly small innovation that could ultimately serve as something of a bellwether in this regard. Nascent programs in several states allow mental health consumers to self-direct their services, managing individualized budgets and functioning as purchasers rather than recipients of services. Hypothetically, these models hold the potential for radically altering the power dynamic between consumers and providers, forcing the latter to sell themselves at the risk of consumers’ walking with their wallets. For a system where the long-standing “catchment” process assigned community mental health providers solely on the basis of a consumer’s street address, this is a breathtaking turnaround. And, in contrast to top-down efforts that might have dubious effects on empowerment, this approach directly asserts the consumer’s authority. However, self-direction initiatives are not yet at a scale that risks any cultural upheaval in mental health care.
health operations. They are very small, entail modest individual budgets, and don’t include self-direction of the full service spectrum. Anecdotal reports indicate that providers are cynical, anticipating fiscal and clinical disasters attributable to poor consumer decision making.

Nonetheless, a core of professionals and policymakers, although mindful of these concerns, is promoting self-direction, peer supports, psychiatric advance directives, and other measures resonating with consumer empowerment. Reminiscent of the expert-driven character of early system reforms noted by Tomes, today’s empowering reforms exist at the discretion of professionals, albeit reflecting some level of consumer input. It would be revisionism to assert that consumer empowerment was at the forefront of the community mental health movement, which was in its heyday when professionals launched early landmark reforms. Yet in contrast to today’s climate of confusion and parsimony, it seems safe to say that early professional proponents of reform emerged at a time of optimism, energy, and innovation, thinking about mental health in broad terms and envisioning an imaginative array of community-based initiatives to supplant the state hospital.15

A sadly prophetic observation from those early years warned that translation of the new community mental health paradigm from legislative language through the various governmental and mental health bureaucracies presented “abundant opportunities for the original intention of the program to be misunderstood, inculcated or lost sight of, observed or disregarded.”16 Indeed, more than three decades later, the beleaguered community mental health movement has eroded to the point at which many users find it little more than a vehicle for delivering medications, sometimes under the cloud of court orders. Although pockets of innovation exist, most consumers are consigned to the same menu of services that perpetuate disempowerment and the bemoaned “revolving door” of reinstitutionalization. Concurrently, lucrative, self-interested provider industries have emerged, whose political prowess exceeds anything realized by the consumer movement. Paradoxically, the very mental health bureaucracies complicit in such commerce also profess their commitment to self-determination.17 This is the convoluted and dispirited world confronting consumer advocates who, with newfound access, seek to somehow make this commitment materialize.

**Fragmentation of authority.** Unfortunately, matters have become even more complicated. For better or worse, at the time of the early reforms, state mental health commissioners were the identifiable system leaders, overseeing inadequate but sizable budgets and having considerable say over hospital and community operations. Today, authority over services and supports critical to mental health consumers is dispersed laterally and vertically through multiple bureaucracies. State Medicaid, employment, and housing agencies as well as their correlates in county and local governments are all key players.18 Few likely see mental health, let alone mental health consumer empowerment, as a pressing priority. So although consumers are now offered a seat at the table—often with interagency representation—the seemingly straightforward question of who is, or should be, seated at its head becomes fairly complex.

**Daunting challenges ahead.** The consumer movement has a pivotal role in bringing meaning to personal and collective empowerment in mental health. As discussed, notwithstanding an air of conviviality and a heretofore unseen opportunity to be heard, it faces daunting challenges. The test in the months and years ahead will be whether the convoluted system can somehow step aside and allow consumer empowerment to demonstrate its impact and its worth.

The author acknowledges the inspirational and enduring efforts of the mental health consumer movement and its allies.
NOTES


14. It is worth noting that the twenty-two-member New Freedom Commission included only one self-identified mental health consumer.


17. Levine, The History and Politics, 185.