Nothing About Us Without Us

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Last week, we were joined in our Priorities in Global Mental Health class by members of [Fountain House](#). Located in midtown Manhattan, Fountain House is dedicated to the "recovery of men and women with mental illness by providing opportunities for members to live, work, and learn, while contributing their talents through a community of mutual support."

I have been lucky enough to collaborate with Fountain House on a variety of projects over the past few years, and their mission and work continue to teach me about the power of community and the potential that is unleashed when we respect and empower individuals with serious mental illness to be full-fledged members of our communities.

1. "We Are Not Alone" In 1944, six former patients from Rockland State Hospital got together to continue a "club room" group that they had begun in hospital. They called it "We Are Not Alone" and shared their stories within the group, painted, and participated in social activities together. After four years, with the help of a John Beard, social worker and psychiatrist, they acquired a building in Manhattan. The building had a fountain in the middle, so they called it [The Fountain House.](#) John Beard promoted the (then) radical idea that people with schizophrenia, bipolar disorder and other serious mental illnesses could work, and that work would be good for them and the community. Thus, from the beginning a foundational piece of Fountain House is the creation of jobs for members, including running the club house.

2. A community with purpose and connection. To appreciate the essential function of a community like Fountain House, we just have to pause long enough from our busy lives to consider for a moment what it would be like for any one of us to have nothing to do, no place to go and no one counting on us. No texts on your phone. No emails in your inbox. No letters in your mailbox (okay... those days may be over). What might be blissful for a while would soon upend our sense of belonging and place in the world. This is what our speakers described: as their illnesses raged, other aspects of their lives receded. Fountain House's vision of a world

where people with mental illness everywhere are able to achieve their potential and are respected as workers, neighbors and friends is an antidote to this all too common outcome. Our guests from Fountain House described organizing social programs, preparing educational lectures, curating a film series. developing professional skills, and speaking to groups like ours as essential activities that restore purpose, connection and meaning to their lives.

3. Some numbers. Fountain House serves about 900 members at any given time. It costs Fountain House about $28,000 per person per year to provide housing, community support services, employment, educational opportunities and social programs. That sounds like money well spent if we consider that a two-week stay in a psychiatric hospital in New York has a [similar price tag](). [According to a study conducted by NYU,]() Fountain House reduces the "revolving door" syndrome of rehospitalization for individuals with serious mental illness. [Membership in Fountain House is associated with an 11% reduction in health care costs compared to what would be expected without such intervention.]() Of course, it may be that individuals who fail to engage in community programs have more complicated illness, which would account for the higher costs. And it may be that some individuals with serious mental illness need more support or care than can be provided at a community-based program, at least on occasion. But these are empirical questions that research can answer so that we more effectively design services and deploy our limited resources.

4. The Silver Center. Individuals with serious mental illness have [shorter life expectancy]() compared to their peers without serious mental illness. This was true for my Uncle Henry who lived with schizophrenia and died more than 20 years ahead of what would otherwise have been his full-life expectancy. This is the case for far too many individuals with serious mental illness. And for those who do grow old, the risks of social isolation are profound. In response to the recognition that it gets even harder to stay connected as we grow older, Fountain House has expanded its services to enhance social engagement and quality of life for seniors. The [Silver Center]() provides programs in a lounge in one of the Fountain House housing units, and with the use of technology, individuals with limited mobility and those living in assisted living or nursing homes are able to reduce social isolation and stay connected to vital services.

5. Fountain House is global. Fountain House was a radical idea in 1944. Today there are over 320 clubhouses worldwide. Clubhouses share the commitment to building communities characterized by respect, opportunity, and engagement. At the same time, each clubhouse is unique and reflects the aspirations and personalities of its members – much like any family or community. [Clubhouse International]() supports communities in building clubhouses that offer people living with mental illness opportunities for friendship, employment, housing, education and access to medical and psychiatric services in a single caring and safe environment. The [World Health Organization is advocating for more community based services for individuals with mental illness](). By all indications, Fountain House, and all the Clubhouses around the world, are at the head of the pack.

When I was a kid, I only saw two options for people with serious mental illness – the homeless man who slept on cardboard on the church steps and my Uncle Henry on a locked psychiatric ward with unremitting hallucinations and delusions. Those images continue to dominate the story of serious mental illness around the world, but members of Fountain House and similar programs are crafting a different script, affirming the power of community and the potential of individuals with serious mental illness to construct lives with purpose, joy and connection.