

Ronald Bassman, PhD
Executive director, MindFreedom International
Board member, Disability Rights International
United States

Because of my own past diagnosis of schizophrenia, my treatments with insulin comas, electroshock, massive doses of Thorazine and Stelazine, I have spent much of my life trying to understand troubled and untroubled altered states, many of which are called madness. I have wondered how we can support the disempowered marginalized among us who must deal with ableism, sanism and various misconceptions about disability. Many of us have painfully learned that once you are perceived as not adhering to the appearance, actions and roles associated with being normal, you are a prime candidate to be captured by a purportedly benevolent health system. Too quickly we learn that being in an institution can cost us the loss of our personal agency.

The highly disproportionate amount of illness and deaths from Covid in congregate settings shines a light on how institutions cause people to lose their value. For the residents, learned helplessness is central to their survival. Institutions stifle a person's development, break the spirit, and work against having access to our natural resilience.

In the United States and in most countries around the world, when someone is hurting emotionally, is confused about life, feels trapped and alone, it is likely that she or he will be confined to a psychiatric institution and forcibly drugged. Removing a person from her or his community is not helpful, ultimately resulting in more harm than good. And with Children who are our most vulnerable and in the process of developing into who they can become, the damage of living in an institution is profound. The isolation from the life of community that is in the ethos of congregate living is anathema to a quality life.

If people are segregated and confined to living in congregate settings, myths, fears, and misconceptions will continue to exist in the imaginations of people who have not had the opportunity to have a neighbor with a disability who they can get to know and maybe even discover a new friend. I wonder if people with disabilities were integral to our communities whether it would initiate the public acceptance to the dismantling of institutions. Diversity when it is experienced is one of the keys to developing empathy and compassion.

One of my favorite quotes is by medical anthropologist, Edward Hall, from his book, *Beyond Culture*, he said: "Failure to fulfill one's potential can be one of the most devastating and damaging things to occur to a person. A kind of gnawing emptiness, longing, frustration, and displaced anger takes over when this occurs. Whether the anger is turned inward on the self or outward toward others, dreadful destruction results."

We have the capacity to develop viable alternatives to institutions where supports that emphasize listening with curiosity, empathy and compassion are essential to encouraging the personal agency that enables a life of quality.