A house is not a home: The great residential divide in autism care

In the United States, a debate about how and where to house adults with autism is dividing autism advocates. New rulings from the Center for Medicaid Services, which oversees the public health care insurance program for people living in poverty or with disabilities, has thrown this debate into sharp relief. The revised rules require that long-term care facilities paid through Medicaid waivers—a common financing mechanism to support adults with disabilities—house no more than four people, be dispersed in communities, and offer significant freedom of access to their residents (https://www.regulations.gov/document?D=CMS-2008-0035-0058). Many autism advocates have hailed this ruling as a civil rights victory in the service of inclusion and community participation. An equally vocal group is very concerned that this funding arrangement will make it difficult for more severely impaired adults who need round-the-clock care to find adequate housing.

This debate echoes the one we have had in the United States for almost 200 years about how to care for adults with psychiatric and developmental disabilities. As we think through providing care for adults with autism, it may be worth revisiting our usually well-intended but often misguided history.

My grandmother died in a psychiatric hospital in 1953, 24 years after she was institutionalized, most likely for post-partum depression. My father was told that his mother died in childbirth and learned the true story from a distant cousin 50 years after his mother’s death. My grandmother’s story is devastating but not unusual. In the mid-1950s, more than 1 in every 200 Americans spent at least one night in a psychiatric hospital (Grob, 1995). There were few effective treatments for serious mental illness and no community supports for people with intellectual disability. Thoughts, moods, and behaviors that differed from societal norms often were pathologized and resulted in institutionalization, even in the absence of significant impairment. The stigma surrounding people with psychiatric and developmental disabilities was such that isolating them was considered the best option (Fabrega, 1991).

Many—but not all—of these institutions were horrible places (Grob, 2014). Academic treatises and investigative journalism exposed serious overcrowding and patient abuse (Archer and Gruenberg, 1982). Research gave evidence of the debilitating effects of institutionalization and of the inability of hospital staff to separate psychiatric disturbance from normal functioning (Braun et al., 1981). In the late 1950s and early 1960s, global sentiment shifted, typified by the Mental Health Act in the United Kingdom and the Community Mental Health Act in the United States. These acts acknowledged the autonomy that individuals with psychiatric disorders should be granted, made it more difficult to hospitalize people, and paved the way for dramatic increases in the availability of community-based mental health care.

In the United States, widespread deinstitutionalization started in the early 1970s (Grob, 2014). Over the next two decades, hundreds of state psychiatric hospitals and centers for people with developmental disabilities closed. The move from institutional treatment to community treatment was supposed to solve two problems. First, long-term stays in psychiatric hospitals contribute to negative outcomes for people with psychiatric and developmental disabilities. The lack of intellectual stimulation, emotional reciprocity, and opportunities to engage meaningfully with the world around them made people worse. Ostensibly, previously institutionalized people now would participate more in their communities. Second, institutions and the practices that occur within them were hidden from public view, which led to little accountability and serious abuses. Moving treatment to the community would lead to greater observability and accountability.

Moving mental health care to community clinics has not solved these problems. People with serious mental illness often live in what have been termed “psychiatric ghettos” or in poor neighborhoods with few opportunities for community engagement (Vick et al., 2012). Today, media exposés of abuses in community settings rival those of psychiatric hospitals a generation before. Complicating matters is that community services often are not up for the task of caring for individuals with more profound impairments. Care often is not evidence based, and community mental health staff positions have been depersonalized, sometimes in the extreme (Institute of Medicine, 2001). Many of those who left psychiatric hospitals swelled the ranks of the homeless (Fazel et al., 2008) and incarcerated (Fazel et al., 2016). These problems have caused some researchers to call for a return to more institutionalized forms of care, hoping for a more humane asylum than those in our past (Sisti et al., 2015).

Today, publicly funded options for residential care for people with psychiatric and developmental disabilities are as flexible as they have ever been, ranging from relatively unmonitored apartments with 1–2 people to segregated farming communities with intensive staff-to-resident ratios, and everything in between. The general trend, often

References

Braun et al., 1981.
Archer and Gruenberg, 1982.
Grob, 2014.
Institute of Medicine, 2001.
Sisti et al., 2015.
in response to lawsuits, has been a move toward community-based options. These options are consonant with social values of inclusions and participation, but there is little hard evidence regarding which setting benefits which type of person. A handful of studies have attempted to examine the effect of housing arrangement on choice and community engagement, mostly for people with intellectual disability (see for example Ticha et al., 2012, 2013), but more impaired individuals who are less capable of making independent choices are more likely to be housed in more restrictive and segregated settings, making determinations of the effects of housing, separate from the effects of these impairments, difficult (Cummins and Lau, 2004). Other outcomes, such as safety, health, life satisfaction, emotional well-being, and happiness, barely have been studied at all (Ticha et al., 2013).

Clearly, we need more research on the effects of different housing arrangements on outcomes for adults with autism. Residential care is the single largest cost over the lifetime of individuals with autism (Buescher et al., 2014); decisions about this type of care may have the most profound effect on their well-being and happiness. Right now, our decision-making regarding which types of placements to pay for and prioritize is based on values rather than data. And, the dichotomy between community placements and more segregated settings may not be the most useful dimension to value or to measure. Perhaps, we should instead consider two other factors: have we maximized happiness, health, safety, and community engagement for that individual (Orsmond et al., 2013)? And, returning to one of the original reasons for deinstitutionalization, have we maximized the observability of care, so that we can be confident of its quality?

I am not naive to the challenges implied by these two metrics. Measures of happiness and life satisfaction, especially for those adults with whom we have difficulty communicating, are very poor (Shattuck and Roux, 2013). Community engagement is a fuzzy construct. Does a heavily supervised visit to the mall with little interaction with others count as engagement? Should we instead identify social capital as a more meaningful construct (Mithen et al., 2015)? What systems, regardless of where housing is located, should be used to monitor quality of care? Debatting and conducting research on the relative merits of different residential settings is important, but not a substitute for focusing on what care is delivered and what opportunities are available in these settings. Incentivizing community-based housing will make care more consistent with many of our societal values and will combat our society’s dangerous tendency to move toward more restrictive settings when they are available, even when it is not in the best interest of the individual. It will not, however, address more fundamental concerns about community participation and observability of care and has the potential to leave more severely impaired individuals behind.

References


David S Mandell