Arguments against Segregated Dementia Care *(abbrev.)*
(Carson & Power, 2019)

The Civil Rights/Human Rights Argument

There is only one group of people – outside of convicted prisoners – who can still be compelled to live apart from others, and that is people living with dementia. Such restrictions infringe on the right to have a choice of housing – a right declared by the United Nations Convention on the Rights of Persons with Disabilities.

The choice of housing is also guaranteed by the United States Supreme Court in their 1999 *Olmstead vs. L.C.* decision, which reinforced the right of people with "mental impairment" to live in an integrated setting for as long as they may safely do so with the necessary supports. Supporting the integration mandate in the Americans with Disabilities Act (ADA; 1990), the Olmstead decision asserts that the medically unjustifiable institutionalization of persons with disabilities constitutes a violation of the ADA. States must provide services to people living with disabilities in the community, as opposed to in an institution, and failure to do so constitutes discrimination. In short, people living with dementia have the right to live in the least restrictive setting possible.

Locked Doors are a Primary Cause of Distress

In the early days of segregated dementia care, Namazi and Johnson (1992) investigated autonomy among 22 residents living with dementia in both locked and unlocked settings. Each resident was observed for a total of 50 hours under each condition. The researchers observed and reported any 'behaviors' which were manifested by residents 30 minutes after encountering either the locked or unlocked exit door. Here's what the researchers found:

> In the five categories of active, verbal, aggressive, sexual, and other responses, there were a total of 1,503 manifested behaviors under the locked door condition. Under the unlocked condition, the total number of reported behaviors for the above five categories was 412. (p. 19)

Among these manifested 'behaviors', "the locked doors precipitated 52 instances of agitated behavior. Under the unlocked door condition, there was a dramatic decline in agitated behaviors…" (p. 20). The researchers continue:

> Among those who were most eager to exit the unit, the experience usually ended when the resident was assured that the door was open and he or she could depart. Several residents held the door ajar with one hand, stepped outside, looked around, and then came back inside. This activity was repeated by residents several times during the morning trials. Once a resident's sense of curiosity was satisfied, i.e., the resident recognized that he or she was not confined within the unit and was free to go in or out, he or she often chose to remain indoors. (p. 20)

In summary, people try to escape places they feel locked in, and locked doors may do more harm than good.

The Fallacy of Homogeneity

Dementia is not a specific disease; rather it is a syndrome – a collection of signs and symptoms involving cognitive function that can follow many different patterns and have many different causes. There are over 100 different diseases or injuries that can result in a dementia syndrome. Within these multiple causes, there are many levels of ability, individuals with many different amounts of reserve, various talents and shortcomings, different cultures, relationships, coping styles… but one kind of living environment and approach to care and support? This constitutes what may be "the greatest misconception in aged care" (Power, 2017): the idea that such a diverse population is alike enough to justify sweeping generalizations about how 'they' should live.

Furthermore, many communities segregate based on the person's identified "stage" of dementia. But staging is a very suspect way of evaluating and understanding people. The scales used are very coarse and reductionistic, and do little or nothing to capture intact strengths or personal interests. This leads to the opposite of individualized care and support as people become homogenized. Such scales will often cause us to underestimate people's capabilities and create environments that restrict opportunities for personal growth.

The (Lack of) Evidence on Segregated 'Memory Care'

In the Alzheimer's Association's Dementia Care Practice Recommendations (2018), Calkins provides a detailed literature review on the topic of segregation versus integration. Here are some notable points about segregated approaches:

> A recent Cochrane review (Lai, et al., 2009) suggests there is a lack of evidence for better clinical outcomes, and other studies demonstrate an increased risk of elder-to-elder aggression or mistreatment (Lachs et al., 2016) and potentially higher antipsychotic use in segregated units (Cadigan, et al., 2012; Powers, 2017b)… Van Haitsma, Lawton, and Kleban (2000), in a well-designed and controlled study, found there were poorer outcomes for individuals who lived on the segregated living area than for a matched sample of residents who lived in integrated living areas. (p. 117)

There are also no established standards as to what such an environment should be. Organizations can create a separate area and call it a "special care unit," but there is no benchmark to tell anyone what that means. In fact, there is only one feature that is nearly universal: a locked door.

The Demographic Argument

Worldwide, a significant increase in the number of people living with dementia is projected; many predict the number could nearly triple by 2050. We cannot continue to rely upon segregated living areas for the increasing population living with dementia, because there will not be enough younger people to build, staff and maintain them. As Calkins (2018) explains: "Beyond the ethics of stigmatization, integration makes sense given the statistics that 40–42% of assisted living residents and 61% of nursing homes residents have moderate-to-severe cognitive impairments" (p. 116).