INFORMATION BULLETIN: ALTERNATIVES TO INSTITUTIONS

NO PLACE LIKE HOME: SMALL COMMUNITY RESIDENCES FOR PEOPLE WITH DEMENTIA

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Preamble

When the public thinks of residential accommodation for people with dementia, it thinks of institutions as the only option even though institutions are the worst possible option for people with cognitive disabilities[1] and this report explains why, and outlines what one of the alternatives is.

Imagine being confused and struggling with severe memory loss as well as high levels of anxiety, then being "placed" in an institution where the corridors all look the same and you can't find your room, where you can't remember where you are, and do not recognize anyone because you are housed with strangers – a lot of strangers. Imagine feeling frightened and alone and hearing people screaming and not being able to get help when you feel like screaming yourself.

That is life in an institution for most people with cognitive disabilities.

It doesn't seem right does it? And yet this has been Ontario's primary residential response to people who are no longer safe in their own homes and apartments.

The public and even many organizations representing people with cognitive disabilities have concluded that the only possible options are retirement homes for individuals at the early stages of dementia,[2] unregulated living environments such as board and care homes, and long term care institutions, some with locked wards. It is a scenario that would be familiar in the 19th Century not the 21st.

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[1] Cognitive impairment is sometimes used to describe mild neurocognitive disorders including memory problems associated with Alzheimer's disease. "Dementia is typically diagnosed when acquired cognitive impairment has become severe enough to compromise social and/or occupational functioning. Mild cognitive impairment (MCI) is a state intermediate between normal cognition and dementia, with essentially preserved functional abilities." https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4104432/
Memory loss and other symptoms of dementia are associated with more severe forms of cognitive impairment, however there are people offended by the term "impairment", hence the use of disability in this report to refer to loss or change in cognitive ability that affects someone's functioning.

[2] "Dementia is the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities to such an extent that it interferes with a person's daily life and activities. These functions include memory, language skills, visual perception, problem solving, self-management, and the ability to focus and pay attention. Some people with dementia cannot control their emotions, and their personalities may change. Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person's functioning, to the most severe stage, when the person must depend completely on others for basic activities of living." https://www.nia.nih.gov/health/what-dementia-symptoms-types-and-diagnosis

Incursion of For-Profit Ownership

The province of Quebec has supported small family type homes for elders who are frail. Usually for-profit and run by the home owners, they do provide social care for three or four people, each with their own bedroom, and part of a household that includes participation with meal preparation and other household activities (Montreal Economic Institute, n.d.).

For-profit companies are also beginning to get involved in providing smaller living environments for people with dementia in the United States in order to meet public demand. Boomers, unwilling to be forced into institutions are starting to drive the demand for alternatives to them. Called adult care homes, they house 5-10 people in regular homes in the community and for-profit companies operate them all across the United States (Clark & Coelho, 2021).

SSAO considers this problematic in light of the care-related problems exhibited during the pandemic in for-profit, corporate-owned long term care facilities in Ontario. SSAO believes that profit has no place in the care of people who are vulnerable to exploitation and is recommending that small community residences or adult care homes be operated by not-for-profit organizations.

One Model: An Adult Care Home for Individuals with Dementia in Toronto

In 1970 Ewart Angus bequeathed funds in trust to the Eglinton St. George's United Church to facilitate development of housing for senior citizens in Toronto. This led a planning committee to develop a smaller setting for people with dementia who were thought to be inappropriately placed in nursing homes.

Inspired by Dr. John Tooth, who had established similar residences in Tasmania, Ewart Angus Homes Inc. became a reality in 1999. The idea was to create a private, non-profit home, licensed as a retirement home in 2013 by the Retirement Homes Regulatory Authority of Ontario - one that would operate on a social, not a medical model of care.

A social model of care stresses the need to build on residents' strengths and to encourage maximum choice and independence and by incorporating strong and meaningful programming in a home-like setting.

Social care employs normal activities of daily living as a basis for programming that provides both structure and security for residents according to their needs and interests, while supporting memory and cognitive functioning. This reduces challenging behaviors like wandering, night wakefulness, loss of social skills and aggression. Self-esteem and a sense of independence are maintained by residents helping with familiar tasks to the degree that they feel able. Residents' natural routines are respected and meal and bedtimes are tied to residents' preferences. Activities that promote a sense of calm such as gentle exercise, music, games, walks, gardening and special celebrations are included, and residents receive personal care as required.

Importantly families maintain ongoing communication with the "home" and are regularly consulted as residents' needs are assessed and their care plans revised. They are encouraged to visit as much or little as they wish and take part in special events and celebrations.

The first dementia care home was opened on Merton Street in Toronto, with Cedarhurst Dementia Care Home on Bayview following in 2005 (Cedarhurst Dementia Care Home, 2016).

Because these facilities are operated as retirement homes there is a high monthly cost associated with them as is the case with many retirement homes so they are not affordable for many people

This is one model, albeit larger than some would prefer, of how to house people with cognitive disabilities in a smaller setting. The facility is divided into four living spaces with 6-7 residents per unit, with one personal support worker, specially trained in dementia care for the residents. The entire home and garden are secure in order to allow residents to wander safely. What this means is that there are still upwards of 24 residents located in a building with specific common areas in one facility. To those familiar with smaller residential settings, this would constitute a mini-institution. Although a more positive alternative than a 200 bed institution, many would prefer to see much smaller residential alternatives to this model.

Responsive Behaviors?

One of the issues regularly raised about the need for more staffing in institutions is the "high acuity" posed by residents who have cognitive disabilities, some health problems and "responsive behaviors". This is simply another term for aggressive acting out, often in response to a barren, unstimulating, uncomfortable, and frightening environment. The case is made to throw more money at these predominantly for-profit institutions in order to deal with this "high acuity".

The fact that the majority of staff that provide care in these institutions - personal support workers (PSW's) are ill equipped, without any kind of trauma-informed or behavioral training, appears not to impede the irrational argument that all that is needed is more money to hire even more staff with little to no knowledge of how to handle these behaviors.

The fact is that this creates an impossible situation since institutions, by their nature, often contribute to aggressive behavior by residents by forcing them to accept institutional routine, assembly-line care, lack of stimulation and meaningful activities, unfamiliar food and people, lack of attention to their basic rights, and an almost complete lack of safety and privacy.

It is quite impossible to provide trauma-informed care, which has been found to be very helpful in the treatment of people with dementia, in an environment that is inherently unsafe and unsupportive.

Trauma-Informed Care Demands Smaller, Safer, Home-Like Settings

There is a connection between post-traumatic stress disorder (PTSD) and dementia that is often nuanced and complex and generally not identified by undertrained staff. Anyone who has suffered

with PTSD during their lifetime is more likely to develop dementia likely because of stress-related changes to their brains and central nervous systems (Qureshi et al., 2010; Yaffe et al., 2010).

Being diagnosed with dementia can also increase one's chances of developing PTSD since it represents a traumatic event, much like any diagnosis of a terminal condition. There are also other stressors that come with aging including complicated grief, repeated loss of people, functioning, and control, and other health crises. For all of these reasons people with dementia are likely to have a higher risk of PTSD and being forced into an institution makes all of this worse, often leading to acting out and sometimes violent behavior.

It can be difficult to determine which symptoms people experience are related to dementia and which to PTSD since hyper-reactivity, anger, memory impairment, inability to concentrate, hyperarousal and susceptibility to triggers in the environment are common to both (Janssen, n.d.).

What is needed is the promotion of a sense of safety, connection and trust – virtually impossible in an impersonal institution. Trauma-informed programming such as adapted eye movement desensitization and reprocessing, exercises, meditation, and breathing intended to calm the nervous system, music and art therapy are also virtually impossible to deliver in an institution but quite possible in a smaller residential setting more attuned to individual's personal needs.

Ontario's Dementia Care Plan? House Them in Institutions

Very few non-profit community residences exist for older people with cognitive disabilities in Ontario, even though non-profit organizations are well positioned to provide them. Instead, thousands of people with dementia are forced to live in institutional settings where they are exposed to opportunistic infections, aggression from other residents, behavioral problems - often as a result of their living environment and treatment - and where they are subjected to assembly-line care with resident to staff ratios as high as 1:18.

Ontario is taking the exact opposite approach to what is needed to provide humane, safe, and comfortable care for people with dementia. As the government did for decades with people who have developmental disabilities, many of whom experience early onset dementia, it is forcing individuals with cognitive disabilities to live in the worst possible places – institutions that exacerbate rather than easing their symptoms, and where poorly trained staff are also being placed in jeopardy.

Institutions are no places for people with dementia. The government of Ontario learned a hard and costly lesson when it institutionalized thousands of people with developmental disabilities. And it apparently was not able to generalize this lesson to care of older adults with cognitive disabilities. It is time Ontario had another kind of residential alternative, and the research supports that smaller is a better alternative.

What the Research Says: Why Small Community Residences Are Better For People with Dementia

When someone can no longer stay at home for safety or other reasons, there need to be 24/7 staffed residential settings available for them - safe places to live in the community with fenced areas to sit, or wander, and daily routines that people may still want to take part in. Specialized programs like trauma-informed breathing, mindfulness, and stress reduction, and perhaps some occupational therapist and volunteer involvement.

We have known since before 2011 that small community homes provide a domestic environment and better quality of life for people with dementia, and they allow family members to get involved. Countries like the Netherlands, Sweden, Germany, and Japan have already taken the leap into this kind of alternative residential support. Many homes in these countries house 10 people together (which more than we would recommend), but even these have shown promise. Housing fewer people together would be a more optimal solution and likely to allow even better care and quality of life.

The programs developed in the Netherlands are not ideal because many are still located on the grounds of non-profit nursing homes. Peoples' rooms are centred around a communal kitchen and living room, some with private bedrooms, some sharing a room. Experienced nursing staff help residents perform household tasks and take part in activities. They are further supported by a multi-disciplinary team that includes a physician, psychologist, physiotherapist and occupational therapist. These are considered "homes for life" (Wiley-Blackwell, 2011).

A Good Idea with Some Flaws

Although most older people with cognitive disabilities fare better with a social, person-directed, rather than a medical model of care, and also do much better in settings smaller than 10 so that they can all have private rooms, even this model has demonstrated advantages in the care and treatment of people with dementia.

The most important positive outcomes are that stability and clarity were provided by normal, informal household routines that encouraged talking, sharing snacks and meals and reading or listening to music. Residents were able to take part in routines that were familiar to them like setting tables and washing up and this reinforced their sense of purpose and identity and caused them to feel at home. No one told them what to do. They were free to mingle with others or spend time alone. Their eating and bedtime routines were their own, not the institution's. Families could visit and get involved in everyday activities and medical appointments, go with them to religious gatherings, or to the hairdresser. The environment was more pleasant for residents and their visitors, and residents got to know and feel familiar with each other and staff.

The setting also allowed staff to provide care more tailored to the needs of individuals, which increased their own job satisfaction and their ability to work with family members rather than being in conflict with them.

The most pressing problems surrounded staff getting too close to residents – although some would not consider that a problem, and some family members not wishing to be very involved. However, overall resident quality of life was much better than in an institution (Wiley-Blackwell, 2011).

In Conclusion

Individuals with dementia and their families need and deserve small non-profit community residences located in their own neighborhoods, but they do not exist in most places. Here in Ontario, funding is instead directed to large institutions - nursing homes, that are the least hospitable places for people with dementia to live.

We can do better than this, but the public must demand it.

Per diems currently paid to for-profit, corporate-controlled nursing homes would be much better redirected to small, non-profit, community based adult care residences in order to provide more informal, home-like and comfortable settings for people with dementia. It is time the government of Ontario shifted its funding priorities from institutions to smaller, more home-like, non-profit settings in the community.

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