

Home for the Holidays

By Yona Lunsky

As December begins, I am looking forward to spending some quiet time with family. My adult children no longer live with me, but we will have some time together later this month. As I prepare to make their visit feel inviting and homey, I've been reflecting on what 'home' truly means.

At H-CARDD, some of our work focuses on the concept of home—what it means, who doesn't have one, and what happens when people are not living where they want and need to be.

Last week, I was teaching a course for older parents of adults with developmental disabilities, focusing on their brain health as they age and the health of their children. Our discussions touched on transitions related to home: planning (and worrying) for children to move out, adapting when they move back in, and supporting family members when they can no longer live at home due to unexpected circumstances or changes in health.

One family shared a creative strategy they used when their family member was hospitalized over the holidays. They brought pieces of home into the hospital room—their loved one's favourite music, blankets with comforting smells and textures, and familiar lighting designs projected onto the ceiling. They also organized a team of friends and family to make sure their family member was never alone. These small but thoughtful actions made a sterile hospital room feel more like home and brought their family member comfort during a difficult time.

Finding Home in Unexpected Places

This story reminded me that, while we can't always stay at home, we can bring reminders of home with us to unfamiliar places. Doing so can have a significant impact on our health and wellbeing, even for those who may not be able to express their feelings in words. It's worth considering which aspects of home are most important to us, so that if we find ourselves in unexpected situations, those around us can bring that sense of home to wherever we are. For people with

developmental disabilities, tools like [My Hospital Plan](#) can help others know them and their preferences in the event of a hospital stay.

In another teaching session last week, as part of Project ECHO, we discussed the case of someone adjusting to a new home after living in the hospital for a very long time. This issue, often called “alternate level of care” (ALC) in Ontario, refers to patients—frequently adults with developmental disabilities—who remain in hospital long after being deemed ready for discharge, because no suitable home is available. This is a serious problem and part of an [ongoing investigation by the Ontario Ombudsman](#).

A Hospital is Not a Home

Our research shows that [autistic adults and adults with other developmental disabilities are much more likely to stay in hospital longer than they need to](#), because they don’t have a home to go to. To address this issue, the H-CARDD team has been working on a cross-sectoral project focused on identifying the principles and core components for successfully transitioning ALC patients with a dual diagnosis (i.e. those with both a developmental disability and a psychiatric diagnosis) into community settings. We recently published a commentary in [Psychiatric Services](#) highlighting this work.

One of the key principles emerging from this work is that a hospital is not a home, particularly for people with developmental disabilities. For those forced to stay longer than necessary, the coping mechanisms they develop shouldn’t be seen as ‘bad habits,’ but rather as survival strategies designed to help them adjust to an environment not meant to be lived in. And, these adjustments—physical, cognitive, and emotional—don’t come easily and can leave lasting trauma.

When someone eventually transitions to a new home, whether a retirement residence, group home, or apartment with support staff, it’s important to acknowledge the challenges and trauma they’ve experienced. This is an important step in helping people build trusting relationships within their new environment and with the people around them. But supporting successful transitions takes time. That is why preparation before a move and ongoing communication between the hospital and the new home, whether temporary or permanent, are so important. It

is easy to fall into “us versus them” thinking, but when it comes to improving people’s health, we are all one big team and we have to work together.

All of this reminds me that even positive changes can be difficult. Each of us can play a role in helping others feel safe, loved, and supported, no matter where they are. By getting creative and thinking of each person as an individual with unique needs, we can ease transitions, both planned and unplanned. And it’s important to remember that what works for one person may not work for another.

As the holiday season approaches, may you find the spirit of home wherever you are, surrounded by kindness and care. And in the coming year, perhaps we can collectively advocate for everyone’s right to live in a home where they can feel safe, supported, and well.

Additional Resources

- The [Successful Housing Elements & Developmental Disabilities \(SHEDD\) Tool](#) offers a list of personal preferences with design suggestions about the physical space of a home.
- [Visit the H-CARDD ALC Project website](#) to learn more about how H-CARDD is helping to address the challenges faced by Alternate Level of Care (ALC) patients with a dual diagnosis.
- In November, Inclusion Canada and People First of Canada hosted the [15th annual federal policy forum on inclusion](#). This year’s theme was Roofs and Rights – Inclusive Housing Policy and People with Intellectual Disabilities.
- The [DSO Housing Toolkit](#) is a library of housing resources to help create a housing plan.

Brain Health-IDD Study

Learn more about our virtual education courses for adults with intellectual and/or developmental disabilities, their families, and service providers from across Canada.

- [Brain Health-IDD Course for Family Caregivers](#)
- [Brain Health-IDD ECHO Course for Service Providers](#)
- [Brain Health-IDD Course for Self-Advocates](#)