



Essays on Aging in Place:

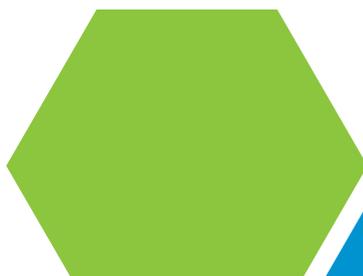
A Guide for Developing Good Policy and Practices, Especially for People Who Have an Intellectual/Developmental Disability

COMMUNITY LIVING
Ontario



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FOREWARD

by Catherine Frazee

“They aren’t nursing ‘homes’, they are institutions.

They aren’t long-term ‘care’ facilities, they are institutions.

End the euphemisms. These are institutions.”

[Gabrielle Peters, 2020](#)

With these words, Peters captures the core truth that animates the pages of this book. An institution is neither a home nor a place of care. An institution is a closed system where problems of human deprivation and indignity are quietly managed, where societal failings are hidden, and where people individually, or, as we now know, by tens of thousands, can die without triggering alarm.

Truth-tellers like Peters, who live precariously at the junction of disability and poverty, have been sounding the alarm for years. Instead of euphemisms, like-minded activists and scholars have written and spoken about [the Gulag](#), and the norms of [carceral practice](#) that reinforce and sustain its authority.

The Gulag is the place where people disappear. It may have “care and protection” spelled out in friendly script on the sign outside its gates, but inside those gates, the rules of order and efficiency prevail. As Harriet McBride Johnson declared, people don’t vanish into the Gulag because that’s what they want or need. They vanish because that is what their government offers: “You make your choice from an array of one.”

The contributors to this volume are not asking for a *nicer* Gulag, a *smaller* Gulag, a *not-for-profit* Gulag, a Gulag for *other* people, people different from themselves. As these essays make clear, we are all in this together, and we need no reminder that the Gulag is just one shift of circumstance

away for each and every one of us.

In many voices, the rising chorus for *aging in place* is a call for abolition. It is a call that unites a broad sweep of citizens – dreamers and pragmatists, builders and agitators, influencers and outliers – from every demographic and electoral sphere. It is a call that accords with evidence that is plainly before us, and equally with the ethos of a post-pandemic awakening to human interdependence and the virtues of care. It is a call that resonates with common sense and common decency, and one that if parsed fairly, transcends partisan ideology.

Institutions have no place in a just and caring society. They must cease to exist, and their decommissioning must be managed swiftly and in good faith adherence to principles of sustainable public policy. Not just people abandoned to fend for themselves, but people accompanied, empowered and resourced to live and flourish in homes and communities of their choosing until the end of their natural lives.

As you are about to read, the studies are in. The pilot projects have delivered. The trials and exemplars are reported in the pages that follow. The blueprint is in your hands, and simply needs scaling. All that is needed now for each of us to age in place, to borrow from John Lord, is political will fortified by human imagination and courage.

Catherine Frazee OC, D.Litt., LL.D. (Hon.), is Professor Emerita at Ryerson University, where prior to her retirement she served as Professor of Distinction in the School of Disability Studies. The Chief Commissioner of the Ontario Human Rights Commission from 1989 to 1992, Dr. Frazee has published extensively on human rights, precarious citizenship, and the activist resistance of disabled people.



EDITOR'S NOTE

The Community Living movement, including people who have a disability, parents, leaders, advocates and service providers have contributed freely to this writing project because they have long known and deeply understood the harmful effects of institutionalizing people in order to receive care and support.

Community Living Ontario (CLO) and Seniors for Social Action Ontario (SSAO) formed a partnership in November of 2020 to investigate and advocate for the changes required to allow all people with disabilities to age in the home of their choice and not in congregate care facilities.

With more and more people who have a disability now being placed in nursing homes, including children, despite a moratorium in Ontario to do so, now is the time to change both policy and practice.

These essays were printed weekly in CLO's Update Friday newsletter, in a special *Aging in Place* series that ran from January to June 2021.

Douglas J. Cartan

ACKNOWLEDGEMENT

Kay Wigle, who passed away suddenly in August of 2021 was an integral part of this writing project as well as the work of SSAO since inception. We are deeply saddened by Kay's passing and miss her profound contributions to eldercare reform to which Kay was so committed.

DEDICATION

This book is dedicated to the life and times of **Donna and Gordon Ferguson** of Brockville Ontario. With a strong vision of how they wanted to live their lives, a home

they owned, a circle of support, good home and health care and an engaged local Community Living Association, Gordon and Donna were able to remain living in their home and community as they navigated the last years of their lives. Gordon passed away at home in 2018 after five years of cancer treatment. Donna passed away in early 2021 from pneumonia after a long struggle with early onset dementia. They both lived life to the fullest while they aged in place.



Gordon, with contribution from Harry van Brommel, is the author of *Never Going Back: The Gordon Ferguson Story: Lessons from a Life of Courage, Strength and Love*

Gordon was a long-time Community Living member and local People First leader who advocated against institutionalizing disabled people.



PEOPLE FIRST OF CANADA

Position: *The Right to Live in the Community*

People First of Canada (PFC) believes that no person, regardless of disability, should live in any kind of situation that promotes or practices congregation, segregation, or isolation. It is our belief that all people, regardless of disability, can live within their community, with appropriate supports. We also believe that people should exercise their right to voice and choice in determining where they live and with whom they live.

Issue and Context

The essential core of the People First movement is the issue of deinstitutionalization. People First believes in the right of every individual to live in their community and will work to close institutions, of all sizes and manner, that inappropriately house people with intellectual disabilities. People First believes that people with intellectual disabilities are inappropriately placed in nursing homes, seniors' homes, group homes, long-term care facilities, personal care homes and other similar settings. Every person should have control over where and with whom they live. Funding should be linked to the disability supports required by an individual, not an agency or geographical area. People's homes should be determined by individual decision, person-by-person, and not based on the availability of beds within agencies. Furthermore, People First recognizes the difference between housing needs and disability supports.

To ensure that all people with intellectual disabilities are living in the community, all large institutions must be closed. Institutional settings as a residential living option should no longer be offered to

people. Policies around individuals must reflect the ideals and principles of inclusive community living for all Canadians and be based on each person's individual needs.

Action Needed

People First of Canada recommends that governments:

- Ensure the human rights of people with intellectual disabilities are recognized, including the right to live in the community,
- Ensure that every Canadian province and territory has closed all of its large institutions for persons with intellectual disabilities,
- Ensure zero admissions to institutions for persons with intellectual disabilities,
- Ensure adequate, accessible, and affordable housing options are available,
- Ensure that government investments in housing are inclusive and in keeping with community living principles,
- Ensure supports are provided to facilitate community living,
- Ensure that institutions are no longer part of the continuum of services available for people with intellectual disabilities.



Imagining Better: The Power of Aging in Place

John Lord is a parent, researcher, and author who lives in Kitchener-Waterloo. John has written extensively on community living, deinstitutionalization, and social inclusion.

As an older parent of a vibrant, healthy daughter with Down syndrome, I worry about what the future may hold for her. Although my daughter Karen is currently engaged in her community, with a job, a network of friends, and a wonderful apartment in a housing co-op, living in Ontario puts her at risk.

Currently there are thousands of people with developmental disabilities in Ontario who reside in long-term care institutions. Many people with Down syndrome much younger than Karen have been forced to live in nursing homes. This is totally inappropriate and is happening because the Ontario government is allowing, and even encouraging it to happen.

There are many reasons why people should never be placed in an institution. Long-term care facilities do not provide the personal support and choice that people receive in the community. Personal control is extremely limited and rigid schedules remove choice and autonomy. We also know from research that people's health tends to decrease once they are placed in a nursing home.

The scariest part for families is that we know the history of institutions. Prior to 2010, for more than one hundred-and-fifty years, our sons and daughters with disabilities were often institutionalized. We know how oppressive and degrading institutions are. We must never forget this history.

As families, how do we begin to address this

serious situation of people with disabilities of all ages being placed in nursing homes?

First, we need to imagine better and demand that the government and local associations provide personalized, meaningful supports for everyone. We need to speak up for a system that rejects the narrative that makes nursing homes sound attractive. We need to embrace "aging in place" and advocate with service providers to honour the vision and reality of what this means. We can write letters to the government and to the opposition parties to push for community alternatives that support aging in place.

Second, we need to connect with allies that support the right of people with disabilities to age in place in the community. Community Living Ontario and Seniors for Social Action Ontario (SSAO) are two groups that are advocating for alternatives. A caring movement of families, researchers, and activists is emerging in Ontario in response to the disastrous way that long-term care has treated people during the pandemic. We can also build common cause with seniors' groups that want to see alternatives to institutions.

Third, within our own families and local communities, we need to implement strategies that reduce barriers to aging in place. Building support networks and support circles is one powerful way to ensure that our sons and daughters have caring relationships in their lives. Over the years, I have witnessed several support circles resist institutionalization and create meaningful support for people to remain in their own homes. Nothing is more important than the valued relationships we build for ourselves and our sons and daughters.

We can imagine better, and we can also do better. In the 1990s, thousands of people with disabilities were moved from long-



term care facilities to the community, but in the last twenty years, the movement has gone in the opposite direction. Now is the time to reverse that trend once again - for the sake of our children.



An Underlying Threat

Audrey D. Cole, mother of Ian Cole and a Past President of Brockville and District Association for Community Involvement (BDACI), is a Distinguished Associate of Inclusion Canada. She has been involved for over 55 years in the Community Living / Inclusion movement and is known primarily for her work on genetic discrimination and, since the mid '80s, on the notion of supported decision making as a rights-based alternative to guardianship for which she was recently recognized internationally.

In an op-ed in December 2020, Judith Sandys and Trish Spindel spoke directly to Canadians who, themselves, have never been forced into insulting, disrespectful and inevitably threatening living (or dying) conditions. They argue that the time has truly come for society to provide appropriate funding and “real choice” rather than what, currently, we broadly refer to as “long-term care” (LTC).

Given appropriate funding and the opportunity to influence the support it would provide, I suspect that very few of us would choose anything other than continuing to age in our own familiar surroundings, perhaps with others of our choice and certainly with the necessary supports to do so. Typically, and obviously, that is known as “aging in place.” Surely, in a supposedly modern society of equal citizens such as that in which we believe we live, aging in place would be the absolutely unquestioned norm.

Were we elderly seniors to be asked what “we” would want in our personal futures, rather than being told what other (usually much younger) people have determined would be in our best interests, I am convinced that it would be neither better LTC homes as we know them nor even smaller group homes. The latter, so easily, as we surely know in our Community Living

Association, can very quickly become institutions.

Now well into my 94th year, I cannot imagine being forced by circumstances beyond my control to live in close contact with people not of my choice. It is not that I dislike other people – although I do admit to having met people I would be quite happy never to meet again!

Similarly, there is an underlying threat faced by my son who has a severe intellectual disability and no capacity to speak or clearly direct his own future. Currently, he is safely supported by his local Association in his rent-geared-to-income home shared with another person with similar needs for care. His support circle will certainly fight for that care to continue but my fundamental point is that it should never, ever, have to be a fight. Rather, surely, it is a human right!

Could any of us truly say we would welcome the almost inevitable fate of our own eventual institutionalization? I doubt it! And as long as we doubt it for ourselves, we are clearly obligated to doubt it for others. Yet we in society as a whole continue to allow that imposition on many elderly people and people with disabilities who have little or limited capacity to argue the contrary. We are even hearing suggestions that the now closed Huronia Regional Centre, Ontario’s oldest institution for people with intellectual disabilities, could be converted into some form of LTC. How could that be? Do we never learn? Is that truly what we are looking for in our futures? I don’t think so.

Systemic consideration of these situations may be undertaken by “us”, but it is never, ever about “us,” is it? Always, it is about “them!” It is only about those we see as needing support as, by reason of age or disability, they become less able to support themselves. Today, we may find it hard to



see ourselves as “them.” Ultimately, almost inevitably, like it or not, “they” will include “us.”

We not only have to see ourselves, potentially, as “them.” We also need to convince government representatives to see themselves ultimately as “them” while we still have the capacity to do so. Our future as equal citizens depends on this.



Why Are Persons with Disabilities Being Placed in LTC Facilities?

Sal Amenta has been an active member of the Community Living movement for many decades at all three levels of the confederation.

As an active member in the Community Living movement for decades, I have served on local, provincial and national boards. In these roles, I championed families in an association that sometimes forgot that families gave birth to the movement while almost exclusively focusing on the needs of individuals with intellectual disabilities. Over the years, however, as my parents aged and passed away after long illnesses, my commitment extended to the family caregivers themselves – those who give so much of themselves to caring for loved ones of all ages, with or without intellectual disabilities.

Today, I have adopted the cause of eldercare because of the horrors we have witnessed in the high death toll among seniors living in long-term care (LTC) facilities during the pandemic. Many families had to second-guess why they had left their elders to such high-risk residences where their loved ones were confined to their rooms and deprived of needed social interaction to protect them from COVID-19. As an active member of Seniors for Social Action (SSAO), I have worked to lobby for the boomer cohort because we are part of Canada's rapidly aging population. Not only will we put great pressure on society to prepare for the senior tsunami that will hit Canada by 2025, when there will be 10 million of us, but we will also challenge governments to change the way they care for us.

In particular, we will challenge the current LTC system because it does not offer us a

variety of options from which to choose. With endless waitlists, we will be lucky to find a bed before we die! In any case, most of us want to avoid going to an LTC facility like the plague! We dread that so much that we want to pose a challenge to those who can make our wishes come true: provide us with options to age in place, at home where we already have a bed, or in small households where we can live out our golden years with friends and family in the community – NOT in an institution!

Despite the tragedies that have unfolded in LTC facilities, we have recently heard of younger adults with disabilities being placed in them. We thought we had finally taken people with disabilities out of institutions twenty years ago, when we found more inclusive settings for them with the help of the "Community Living" movement. And yet, here we are again, placing adults prematurely in nursing homes because, evidently, there is no other place for them to stay!

But we know that thousands of adults with disabilities are safely and successfully living in small homes with others of their own age, where their needs are met. Why is this solution not viable for all other social groups? It is a question of will since the costs of living in either place are comparable.

Have we lost our commitment to the principle of inclusion? In placing adults with disabilities in LTC facilities, we are reverting to the old-fashioned, exclusionary treatment of persons with disabilities. If so, we are losing our faith in community. We must immediately stop this practice and question our motives to ensure everyone, without exception, is treated with due respect. It is a case of human dignity.



The Importance of Our Autonomy

*Volunteering with various organizations to flame the social change movement, **Joyce Balaz** has been advocating for persons living with disabilities to have equitable access to the supports necessary to live an everyday ordinary life in the community. Joyce holds leadership roles in the Individualized Funding Coalition for Ontario, Ontario Independent Facilitation Network, Family Network Thames Valley and Family Alliance Ontario.*

For me, the most important aspect of aging in place is that of maintaining autonomy over one's life. Having choice and control!

Why is this so important?

Having choice and control is what gives a person ownership over their lives. Too often when people access services, that ownership is lost. It becomes about the service agency schedule, staffing capacity, and rules and regulations among other things. These are all implemented to ensure the system runs smoothly and stops being about what the person actually needs or wants to allow them to continue to live a contributing life of their choosing.

What the pandemic has so clearly illustrated is that people in congregate settings were denied their rights to do as they wished. They were denied the right to be with their loved ones. They were denied the right to leave their so called "homes". They were denied the right to make decisions about their own lives. Some were even denied access to medical care, which for some resulted in untimely death.

In contrast, people who remained in their homes maintained their freedom to decide how they responded to the threat of COVID-19. They could choose to self-isolate, they could choose not to go

shopping, they could choose who came into their home, and they could choose to accept the risk that came with a hug.

When one can age in place, that place is one's home. And, like the old adage, "a man's home is his castle", every person should rule as a king in their castle. As ruler, a person has the ultimate control.



Time to Provide Funding and Real Choice in Long-Term Care¹

Judith Sandys is a former dean of community services at Ryerson, a long-standing teacher and advocate for vulnerable people and a member of Seniors for Social Action Ontario.

Patricia Spindel is a retired professor and former associate dean of health sciences from Humber College and the University of Guelph-Humber, and a seniors' rights advocate.

Many long-term care facilities have shown that they cannot provide even basic care to their residents. Developed on a 19th-century poorhouse model, they are inevitably dehumanizing and, almost without exception, dangerous places. COVID-19 has brought this lesson home.

In 2009, the last of the government-operated institutions for people with intellectual disabilities closed, followed by major class action lawsuits exposing the horrible conditions endured by those who had lived there. No one, irrespective of severity of disability, should have had to live in such places. Paradoxically, at the same time as Ontario was closing down institutions for people with intellectual disabilities, it was ramping them up for older adults.

Societal ageist and ableist perceptions devalue seniors and people living with disabilities. Society values health, wealth, beauty, independence and achievement. Those who are not perceived to measure up are at greater risk, often seen as a burden and drain on society. They are regularly placed in environments that are harmful to their health and well-being. Yet,

¹ Part of this article was originally printed in the Toronto Star as an Opinion piece, 30/12/20

they include people with rich histories, who have loved and been loved as children, parents and grandparents, and played a part in building Ontario. Surely, they deserve better.

With Canada spending [six dollars](#) on institutional care for every one dollar spent on in-home care, many older adults and younger people with disabilities are forced into these largely for-profit institutions, following the money. With public expenditures at [0.2 per cent of GDP](#) spent on home care, a grossly inadequate and overly bureaucratic system has been created that renders any notion of choice meaningless. Admission to LTC happens in the absence of other options.

The Toronto Star has excelled at pointing out the deficiencies in care between for-profit, and municipally-operated and non-profit facilities. What few have mentioned is the impact of institutionalization itself. People with intellectual disabilities who were institutionalized were almost all in facilities operated by the government or by non-profit boards. In contrast, the vast majority of residents now live in LTC facilities operated and/or managed by for-profit corporations – many large, often multinational bureaucracies whose main mission is to generate the highest possible profits for their operators and shareholders.

As research by the Star and others has shown, COVID-19 outbreaks in non-profit facilities were significantly less devastating than in the for-profits, especially chain operations. So why has government's response been to provide increased funding to the for-profit sector, rather than invest more heavily in the not-for-profit community-based sector, in order to provide residential and in-home alternatives? This has increased an already huge funding and service imbalance, as the bulk of public money has been directed



toward places in which seniors say they do not want to end up – institutions. Where is the funding for a comprehensive and flexible community care system that would offer people real choices?

Of course, the for-profit sector welcomes the expansion of the number and size of facilities. That maintains their status quo. But why is government complicit in supporting a system that commodifies and exploits vulnerable citizens for the enrichment of others? No government should place the interests of for-profit chain operations with a demonstrably poor track record above the needs of citizens.

With 22,000 people dying in LTC facilities every year, the answer is to stop funneling people from hospitals into them. A fully funded non-profit community care system would do that. Residential and in-home service options would help greatly to downsize and eventually eliminate the public's forced reliance on

these institutions. Younger people with developmental and/or physical disabilities and those with serious mental illness can – and should – be repatriated to smaller shared living and staffed community residences now.

Municipalities and non-profit community care agencies are in a good position to drive the needed change if only government would partner with them.

Government needs to get started in creating real choice. End the funding imbalance between institutions and community care. Move into the 21st-century and join other progressive jurisdictions that have already made the change, and greatly increased quality of life for elders and people with disabilities.



It's Time to Shift our Thinking on Long-Term Care¹

John Lord, an order of Canada recipient, is a researcher and author living in Waterloo. He is the author of several books, including Pathways to Inclusion: Building a New Story with People and Communities. He is a member of Seniors for Social Action Ontario.

There is widespread agreement that the crisis in long-term care has been exacerbated by the pandemic. While the failures in long-term care have been well-documented for more than two decades, there are now calls to 'fix' the crisis that continues to include significant deaths of our elders. There are two approaches being advocated by critics, families, academics, and advocates.

The first approach calls for more staffing, increased number of hours of care, and more accountability for the homes. While this approach seems to have merit, it assumes that one can improve long-term care with more money. The goals of this kind of reform are narrow, ensuring that large institutions will continue to be the focus of long-term care. The government of Ontario strongly supports this approach and has recently allocated \$1.75 billion to build more facilities.

The second approach that is gaining momentum is focused on alternatives to the institution. Support for this position comes from Seniors for Social Action Ontario, the Canadian Association of Retired Persons, the Ontario Community Support Association, the Ontario NDP, and several physicians, such as leading gerontologist Dr. Samir Sinha. The goal of this reform calls for us to understand the systemic issues in long-term care and to create meaningful community alternatives to institutionalization.

¹ Part of this article was originally printed in the Waterloo Record, 1/02/21

Research is clear – people's conditions get worse after they enter an institution. Frail elders often suffer with chronic pain, dementia, or other illnesses. In a long-term care facility, suffering unnecessarily increases, brought about by a rigid, institutional system that focuses on disease rather than wellness.

Lack of personal control is also standard in institutional care. It is no wonder that physician and author Atul Gawande has found that the most common complaint he hears from nursing home residents is "it just isn't home."

The pandemic has shown that high rates of infection and social isolation are two other significant impacts of the current long-term care system.

People often have a difficult time imagining a long-term care alternative to large institutional buildings. In part, this is because our culture has ingrained the 'nursing home' image in our minds. We will need imagination and courage to rethink and redesign a system that is personalized, community-based, and focused on well-being and dignity. The recent report, "[Aging Well](#)," by Don Drummond and Duncan Sinclair of Queen's University, proposes such a redesigned holistic approach for long-term care that considers health-care needs in conjunction with housing, lifestyle and social needs.

As we look around Canada and the world, we can learn from existing redesigned systems. Several countries, mostly in Europe, have reallocated significant resources from institutional care to community supports and home care. Countries such as Germany, Denmark and Japan have done much better than Canada at lowering the rates of institutionalization of frail elders. As an example, [in Japan](#), 33.6 per 1,000 people aged 65 and older



are institutionalized compared to Canada at 58 per 1,000 in the same age range.

Redesigning long-term care in Canada will need to focus on three major areas.

First, since [Canada spends far less](#) on home care than many other countries, we need to fund enhanced home care that enables more people to remain in their own homes. Home care that provides funding directly to the person and their family will enable people to have control over the supports they require. Allowing people to age in place is also cost-effective. As Dr. Sinha points out, Ontario spends \$183 per day to support a high-needs person in a nursing home, compared to just over \$100 per day to provide home care.

Second, we need to fund caring community networks. [Aldred Neufeldt](#), professor emeritus at the University of Calgary, points out that neighbourhoods, apartments and condos exist where many elders reside that can create supportive connections. [Radical Rest Homes](#), based in Montreal, offers workshops and supports for people to create networks where people share staff or create shared living situations. Governments need to support this kind of cost-effective innovation.

Third, we need more community housing options for those who require congregate care. These can be homelike settings where people have choice and connections with family, friends and community. These should be non-profit entities and could be provided by community support organizations or municipalities. The Green House Project in the United States is an example of such a community enterprise, and there are Canadian projects in the development stage.

It is time to rethink our approach to long-term care and to embrace more alternatives to dominant institutional models. With an aging population, the demand for long-term care is expected to double in the next 20 years. Since polls show more than 90 per cent of Canadians do not want to end up in a nursing home, we need to take bold action to ensure that our elders can live in dignity as they age.



Stop Normalizing Long-Term Care for People Who Have Developmental Disabilities

Chris Beesley, CEO, *Community Living Ontario*

In the Aging in Place series, we have highlighted the issue of people who have intellectual or developmental disabilities (IDD) being put into long-term care (LTC) facilities, well before the age of 65. Neither I nor any member of my family, friends or colleagues, have ever expressed a desire to live in a long-term care facility, at ANY age. Yet somehow, we've decided that grouping one vulnerable, devalued group and warehousing them with another, makes sense. After all, what could possibly go wrong?

Unfortunately, we have normalized this behaviour by:

1. **Developing guidelines on transitioning people from living in the community to living in an LTC facility.**

Since it is written and validated by many, those who are in leadership positions and have come to our sector more recently may see this as a standard operating procedure.

2. **Creating the illusion of choice.**

Imagine a person who is fifty years old and lives in the family home suddenly finding themselves alone. The choice between LTC and nothing is no choice. A rock and a hard place should never be considered a real choice.

3. **Saying "fifty is eighty for people who have IDD."**

I have heard many times, that being 50 years old with IDD is like being 80 for the rest of the population. This is yet another label that we place

on a whole group to rationalize how we treat people, allowing us to sleep better at night. While some conditions associated with IDD predispose a person to certain health-related conditions which might cause a person to age more quickly, the same can be said for the myriad of conditions that each of us may be genetically predisposed to such as arthritis, asthma, early-onset dementia, heart conditions and various cancers. If people who have IDD are aging more quickly, it is largely our fault. Lack of equitable access to the social determinants of health will do that to a person.

4. **Not heeding the lessons of our institutional past.**

In 2013, Ontario's Premier apologized for our long institutional history. She acknowledged them as dangerous, segregating, congregating, and isolating places that lacked oversight and accountability. They lacked proper health and safety standards. They lacked personal support and stimulation. One need only look at the military's [recent report of conditions](#) in LTC to see the tragic similarities, not to mention over 3,800 COVID-19 related deaths.

5. **Lack of aspirational expectations.**

Through our medical, educational, and social policies and practices, we teach people to expect less and to be less. Under this lens, ending up in an LTC facility at 35 is simply the natural progression of a devalued life.

So, what should we do?

1. **Shut the front door!**

We must revise transfer admission guidelines to de-normalize this practice and take a community-first approach. We must create



guidelines that will allow people to age in place and look to agencies who are already doing it well.

2. Ensure real choice.

Shouldn't a person who is in crisis be entitled to the best we have to offer, rather than an overflow option as the only choice? We've started down the road of mandated services with the minimum \$5,000 Passport allocation and the de facto entitlement to support for youth who are wards of the state and are transitioning to the adult system. We should also mandate supports to those who are in crisis and to those who are at risk of a long-term care facility placement.

3. Coordination between ministries.

It will require significant coordination to successfully engage families and people in LTC to assist with repatriating willing people to their community. Policies, protocols and resources between the Ministry of Children, Community and Social Services, and the Ministries of Health and Long-Term Care will be a must. It will also require coordination and cooperation between the

government and the agencies that will be involved with welcoming people. Let's get started!

4. Raise the bar of expectations.

None of us aspire to live in a nursing home. Consequently, we must redouble our efforts to inspire possibilities and raise expectations for lives in community that are typical for all, regardless of label. We should all be offered the choice and the matching supports that allow us to age in place in our home for life.

Each of us must commit to supporting these actions by working together with the government to ensure people can remain in their home and community as they wish and to welcome people back into community. I believe we are ready and willing to do this.

After all, we've done it before. It's time to do it again.



Make Aging in Place a Real Choice: We Can Help

Alan McWhorter has worked for over 50 years at the local, provincial and national associations of the Community Living confederation and currently assists the Provincial Executive Directors Coordinating Committee.

In my 50+ years with Community Living, I have known only one person who wanted to return to an institution. In 1972, that man was brought out of the institution where he had grown up in Orillia. There he had enjoyed a favoured role delivering mail to the staff, and he generally had the run of the place. He found his Toronto group home and sheltered workshop too restrictive, and he resisted in every way he could. Eventually his wish was granted and another person came from Orillia to take his place.

Other than that singular exception, I have never known anyone who wanted to live in an institution. On the other hand, I have known many who tried desperately to get out. It is a source of satisfaction that I have played a part in some of them succeeding.

In 1971, Walter Williston reported to the Minister of Health an extensive list of deficiencies in Ontario facilities housing about 5000 people with developmental disabilities. In 1973, the Progressive Conservative government published "A New Policy Focus" and began returning people to the community. The policy of community living has been embraced by every government since, and the last of those institutions closed in 2009. Subsequently, former residents prosecuted and won a class action against the Government of Ontario. The Premier publicly apologized for harm done to people while in the care of those institutions.

Institutionalizing whole categories of people is not unique to those with disabilities. In 19th and 20th century North America, large industrial/correctional/medical-style institutions were the common response of public authorities to populations seen as problematic in some way. Child welfare took the form of orphanages. Indigenous children were taken by force to residential schools run by religious organizations. There were homes for "wayward girls", and "gaols" for people whose behaviour offended the community. No one chose to live in any of those places.

Sustained advocacy over decades gradually shifted public policy away from institutional responses for some vulnerable groups. Residential schools and orphanages are gone, but the pain they caused is still felt by those who survived them. Memories and records show that even institutions founded by well-meaning people for humanitarian reasons fail. Over time they slide into an operating mode that causes harm to the people they were meant to help. Institutions invariably impose a human management model that involves isolation, regimentation, and dehumanizing emotional, and often physical, harm. This is a pervasive and ubiquitous pattern that transcends cultural and national boundaries.

Operators of today's long-term care institutions may argue that seniors have chosen to live in these facilities. Many of us have known women and men who made that bitter choice to avoid becoming a burden to their children, yet people can only choose from the options available to them. That doesn't mean that an institution is what they needed or wanted. When Community Living Ontario was formed in 1953, many families had made the agonizing decision to institutionalize a family member because nothing else was available. Then they spent a lifetime changing that situation



for the next generation by organizing, building community services, changing government policy, and advocating for deinstitutionalization.

LTC institutions are places no one aspires to live in. A transformation of arrangements for the care of seniors is urgently needed, and it is not more LTC beds. The situation is like what Walter Williston saw in 1971, and the solution is similar too. LTC reform should begin by increasing support for people to age in place, thus slowing admissions to facilities. At the same time, people who wish to leave LTC should be supported and enabled to do so through individual planning, clear targets and deadlines, and adequate funding for community alternatives. This process must be personal, respectful, and collaborative.

If we are to transform care for seniors, there are four essential ingredients for success: focus on the individual; emphasize flexible arrangements tailored for the person; help individuals and small groups develop the supports they need where they already live; and if congregate housing is needed for some, small and dispersed is the only way to provide suitable arrangements.

Ontario has already learned these lessons. It's time to apply that learning to long-term care. Public resources should be diverted from LTC institutions and applied to supporting people to age in place in the community. We in the Community Living movement know how to do this. We can help.



Long-Term Care Facilities Are Not Normal – for Anyone

Kay Wigle is a retired Coordinator of the Developmental Services Worker Program at Fanshawe College and a member of Seniors for Social Action Ontario (SSAO)

(Editor's note: Kay suddenly passed away in August 2021 while this book was in the process of publication. Kay was integral to the advocacy and activism against the institutionalizing of people with disabilities throughout her adult life.)

A question frequently asked is, “isn't part of the normalization process that people with developmental disabilities enter long-term care (LTC) facilities when they are seniors?” My answer – it is not normal for *anyone* to live in a LTC institution.

LTC facilities by their nature deny individuality, autonomy, and self-determination, and they eventually break a person's spirit. Many people with developmental disabilities already did their time in institutions. The Ontario government apologized for the history of neglect and abuse people experienced while institutionalized. There was a successful class action lawsuit. So why is it considered acceptable to once again place people with disabilities in LTC facilities?

There are currently thousands of people with developmental disabilities in LTC, some well under the age of 65. These facilities are becoming a dumping ground when there appears to be no other options. Institutional care is stigmatizing and it leaves the impression that people living in LTC facilities are no longer of value to society or their communities.

People with disabilities have experienced discrimination based on their disability, while seniors experience ageism. Neither stereotype has a place in our society. One of the justifications I've heard for institutionalizing people in LTC is they

are better off with their own kind. This assumption would mean that because I am a senior, I should just hang out with other seniors because, after all, aren't we all the same? I can tell you: I don't like all seniors and that is because aside from age, we don't necessarily share common interests.

The same applies to people with disabilities; just because they have a disability does not mean they are the same, or have the same needs. We must value people's unique talents and gifts, and let them decide how they want to be supported and with whom.

Over 90% of seniors say they do not want to go into LTC. Then why hasn't the LTC system learned from the errors of past institutional practices? I have heard people argue long-term care homes are not institutions. To be clear, they are.

Ontario already has success with deinstitutionalization and the development of small community homes, individualized supports, and direct funding where things are familiar and comfortable. People's quality-of-life matters, regardless of age or disability.

The Community Living movement from institutions to community homes now needs to be applied to LTC. The blueprint is there, it now takes the political will to make the change.

There are many horror stories about the COVID-19 pandemic and people dying alone in LTC. This includes people with disabilities. It is devastating to imagine your loved one taking their last breath without someone who loves them being at their side, holding their hand. But this has become a reality that we hear repeatedly in the news. Surely this tragic experience as a result of the pandemic in LTC has to be the impetus for change in Ontario.

I've had the privilege of knowing many people with disabilities. When signing



the papers to be a legal guardian for one woman with a developmental disability, she made her wishes clear as she was dealing with issues related to aging. She wanted to die at home and if I didn't respect her wishes, she told me she would come back and haunt me.

Strong words and a clear message.



Aging at Home Inspired by Gord Ferguson's Story

Douglas J Cartan, co-founder Seniors for Social Action Ontario (SSAO), former Executive Director of Brockville and District Association for Community Involvement (BDACI) and long-time consultant to Community Living Associations in Canada.

As long-time Brockville Association Board member, self-advocate and People First member Gordon Ferguson considered his failing health in 2018, his last year of life, and asked his circle of friends and supporters not to place him in a nursing home. He had good home, health and personal support, and wanted to stay in his home with his wife. Gordon knew the effects of being institutionalized after 17 years growing up as a youth at Rideau Regional Centre in Smiths Falls. Gordon knew what it was like to be away from family and friends, to be controlled by others, to have life strictly regimented, to be kept from his interests, to be bored with no opportunity to learn things or contribute in some way, to be lonely, harmed and hurt. Without saying it, Gord knew the value of *aging in place* in your home for life with family and good people around you. And that is what happened.

Unfortunately, so many people with disabilities and older adults in long term care institutions (also called nursing homes) are not sharing Gord's experience of *aging in place*. The COVID-19 tragedy that brought so much harm and death in these institutions is unprecedented. With more than 3,700 deaths, and over 15,000 infections and rising, we are seeing one of the worst tragedies in recent memory unfold before our eyes. Ontario's Doug Ford government has been unable to do much about it. In response, however, the Conservative government did pass legislation last summer to make it more difficult for family members to sue for negligence in the treatment of loved

ones who died in these facilities. Many seniors who died were also experiencing dehydration, malnourishment, abuse and neglect as reported by the Canadian Armed Forces who were called in to several Ontario nursing homes last spring. Many sick, frail and elderly residents were not permitted to be transferred to hospitals. They were not valued enough and the consequences have been devastating.

One of the key lessons for us all, but especially for family members who are vulnerable because of their disability, is that home care is a critical component of a comprehensive, community-based, 21st century elder care system.

People with disabilities will age and all people who age are likely to become disabled in some way.

The current home care system in Ontario that assists about 700,000 people is not nearly good enough to meet people's need and desire to remain at home as 95% of seniors demand. The Home Care option is not nearly ready to deal with the huge numbers of baby boomers that are on the cusp of needing more home and health care and alternatives to the large long-term care (LTC) institutions.

Today, there are thousands of people who have a developmental disability in LTC institutions. None *should* be there. With adequately funded home and health care and small supported living situations, we know that all people can be accommodated in their home and community, lifelong.

It is time for all Ontario voters to raise their voice to their political representatives and demand a better community-based home and health care system that allows people to *age in place* as they wish, or alternately, if that is not possible, in small supported living arrangements tailored to one's needs.

Gord and Donna Ferguson were able to age



in place and die as they wanted because of a clear desire to do so, a home that they owned, paid support from several sources, a very committed local Association for Community Living and a circle of friends and allies who helped out. This is a recipe for successful living and passing away.



An Illusion of Care

Linda Till is a Co-Founder and Systems Policy Advisor with Seniors for Social Action Ontario. She is a complex care specialist focusing on system analysis and system change recommendations and activities related to children and adults with complex needs as well as vulnerable elderly people and has had extensive involvement in the deinstitutionalization and the inclusive education efforts in Ontario. Linda is also a parent of a daughter who had significant challenges.

Glowing descriptors of comprehensive person-centred care are promised by long-term care facilities (nursing homes), creating a compelling sense of assurance that residents in these facilities will receive exceptional care. Yet the realities, as clearly documented in multiple investigative media reports, task forces and advisory panels, uncover the extent of the illusion within those promises.

A comprehensive review of the extent of this illusion shows that certain groups of people are disproportionately impacted, most notably people who have a developmental disability, whose devaluation within society is magnified in these congregate facilities.

The harm of institutionalization is inherent in the model itself. Control, standardization, regimentation, loss of personality and diminished connection to community and family have deeply affected those whose support depends on institutional care. Advocacy efforts over the previous 50 years contributed to closing all government-run institutions for people who have a developmental disability by 2009. Since then, government-led policy and procedure has resulted in the institutionalization of thousands of people with developmental disabilities into LTC facilities.

Well before the COVID-19 pandemic shed

an increased amount of scrutiny on these settings, the failures within the sector were abundant. The pandemic exacerbated those failures, laying bare the fact that the institutional (congregate) model of care simply cannot meet their stated and mandated responsibilities towards their residents.

Efforts to mitigate the harms have been largely unsuccessful – extra staffing from outside organizations has proven to be very problematic. Residents are often perceived to be the responsibility of outside staff placement agencies. The failure of dignified, skilled care and support is exacerbated due to a revolving door of strangers called in to assist with people's most intimate support requirements.

Many within community living know the rigours of government compliance reviews, and might justifiably presume similar attention would exist within the LTC sector through Ministry of Health inspection processes. However, therein lies another illusion within this system. As Geriatrician Dr. Samir Sinha has bluntly stated, “[t]he inspection process is broken”. Failures to meet the standards set out in the governing legislation have been extensively documented, along with a high frequency of neglect, abuse, and assault. The needs of the resident population often exceed the capacity of the facility staff, and chemical restraints in the form of inappropriately prescribed drugs to achieve a level of compliance and sedation abound. While the sedative effects achieve the desired facility-driven goals of control, corresponding side-effects often lead to severe health threats.

The extent of the concerns in these settings has prompted the initiation of multiple class-action lawsuits, some new and some already underway before the pandemic. As the saying goes, “where there is smoke, there is fire”. Clearly, there is an uncontrollable fire underway within



this system.

To ensure the current and future well-being of people with developmental disabilities, every effort must be made to turn the tide that has resulted in so many being admitted to these facilities. It is essential that we honour the long-established principles of community living for all and build capacity to ensure that all those we care about are enabled to live life-long within their own homes and communities.

Homes For Life...We can do this!

Full Research / Opinion Paper Reference:

Till, L. (2021). An Illusion of Care: Promise vs Reality of Long-Term Care Facilities. Seniors for Social Action Ontario.

<https://d5bb3c6f-31a3-47ef-a85b-5c06ab03f844.filesusr.com/ugd/>



Redirect Our Social and Financial Investments

Peter Clutterbuck is retired after a 47-year career mostly in the non-profit human services and social development sectors, working with organizations at the local, provincial and national levels. Core values and principles learned in the Community Living movement in the 1970s and 80s shaped both his professional practice and volunteer life in the decades since.

The statement that most caught my attention in the Ontario COVID-19 Long-term Care Commission Report (released April 30, 2021) reads:

The average age of long-term care residents . . . is 84. The Commission heard that residents typically enter a long-term care home in the last two years of their life, and that approximately 22,000 long-term care residents die every year. (p. 41)

Since a [recent survey](#) found that nine out of ten Canadian respondents prefer to live in their homes as long as possible, one wonders why society cannot manage its resources so that wish could happen for all to the end of life. Why concede that the last few years should unfold for so many in an environment as foreign to home, family and community as imaginable?

But, more shocking to me was the sentence in the report immediately following the above statement:

Of the more than 78,000 residents currently in Ontario long-term care homes, a small proportion are younger and have needs that require the assistance of long-term care.

I understand about 2,000 of these “younger” residents are persons with

intellectual challenges and that nursing home placement for persons with developmental disabilities is occurring more frequently. This, even though decades of experience here and in other jurisdictions show that even the most vulnerable individuals with complex needs can live successfully in community. Other than lack of political will and bureaucratic convenience, there is no reason for reviving institutionalization of even small numbers of this population into long-term care nursing facilities.

Ironically, what we have learned about supporting community living based on individual needs in the last five decades could not only reverse this sad trend to re-institutionalization, but also liberate some of our senior population that reside in these facilities, or at least stem the flow of referrals into them until they are no longer viable operations in five to 10 years or so.

Still, the Commission devotes much of its attention to improving the facilities and operations of a system that is fundamentally contrary to what Canadians would choose for their last years. It gives only passing reference to existing community care and support models in other jurisdictions successfully demonstrating real alternatives.

What the community living movement has shown is that ploughing capital into large, special facilities to house people with complex needs of whatever age is a bad investment with life-limiting and even detrimental outcomes for residents. Upgrading or building new congregative facilities with more “beds”, however, is the easy solution and frequently the only option for families with aging parents – and now, it appears, younger adults with complex needs. This “contains” the issue, until, of course, a pandemic exposes its failings and infection and death counts arouse public outrage.



The alternative is challenging to implement but doable and requires that we redirect our investment of both financial and social capital by:

- Supporting individuals in the identification of their own needs and how they may be met within their community of choice;
- Engaging families and friends where possible in this individualized planning and implementation process;
- Arranging the appropriate array of service supports, including highly specialized modes, for delivery in home and/or community; and
- Creating and implementing individualized plans that extend beyond care and maintenance to include personal fulfillment and community engagement where desired.

The main ingredients of this approach are people – family, friends, service personnel – and access to highly individualized financial resources to meet the cost of daily living as well as the extraordinary costs of living that people with complex needs require. Stable home bases are critically important, and they

can be in a family home, independent living, or at a very small community scale. The “residence”, however, should not be the life-defining aspect of the individual’s experience regardless of age, health status, or physical or mental limitations.

This model of care and support has worked for persons with even severe physical and developmental challenges. Political will and policy and resource commitments could make it universal to all vulnerable people now in long-term care facilities or at risk of placement in same.

The promise for non-senior adults with complex needs is a more fulfilling life journey. And, for frail and dependent seniors, one wonders whether not just the last two years of their lives but perhaps the last decade or so to end of life might not be more fulfilling as well.



Understanding the Effects of the Assumptions We Hold

Judith Sandys, now retired, is a former Dean of Community Services at Ryerson University, as well as having been an Executive Director for Community Living associations for 13 years.

Invariably, the assumptions we hold about any group of people – about what they can or cannot do, what they want and what they need – have a defining impact on how we act in relation to members of that group.

There was a time, not all that long ago, when many assumed that people who had intellectual disabilities belonged in large institutions. They assumed that such people would not be safe in the community, that they needed the care and protection that institutions were presumed to provide, that they would be happier with others who also had intellectual disabilities, etc. As we know, all too well, these assumptions led to the development of large government operated institutions that incarcerated thousands of people with intellectual disabilities, subjecting many to dehumanizing and brutal conditions.

Over time, these assumptions changed and we assumed that people with intellectual disabilities belonged in the community, indeed that they needed to be in the community and that the community was better when everyone was included. These assumptions led to significant changes. Today, in Ontario, the large government-operated institutions for people with intellectual disabilities have closed, and while the journey to full inclusions is far from complete, thousands of people with intellectual disabilities – including many who are survivors of these old institutions – are living in the community.

But there are still some damaging assumptions that many hold that continue

to put some people with intellectual disabilities at great risk. An example of this is the mistaken assumption that people with intellectual disabilities age faster and die sooner than do those in the general population. Yes, there are some people who have intellectual disabilities who do die at an early age (often because of serious health issues related to their disability). However, unless they have a serious health condition, once a person with an intellectual disability is an adult, their remaining life expectancy is usually not all that different than the general population. The impact of this assumption is that older people with intellectual disabilities are often treated as being very old, when in reality, they are not that old.

While none of us know how long we will live, studies indicate that healthy eating, frequent exercise, meaningful activity, mental stimulation, and close personal relationships are associated with increased longevity. And if they do not contribute to a longer life, they certainly contribute to a better one. Unfortunately, a good many older adults with intellectual disabilities are assumed to be beyond the point where these things matter, whose days are filled with sitting around doing nothing, day after day after day. “Yes,” we are told, “he’s only 62 but, you know, these people age more quickly...” Or, “she retired (at 58) when the workshop closed down and now she just likes to chill out and take it easy.” This level of inactivity is not good for anyone, regardless of their age.

When we treat someone as if they were much older than they are, or are too old to do much of anything, chances are that they will internalize and act on these perceptions, thereby reinforcing our initial assumptions. Lack of stimulation and meaningful activity hasten the aging process. Ultimately, this denies some people with intellectual disabilities many years of stimulating and enriching activity and increases the likelihood of them being



admitted to a long-term care facility.

We must challenge these damaging assumptions and actively support older adults with intellectual disabilities to lead good lives, at home, filled with meaningful activities and important relationships. Of course, as is always the case, as people get even older, they may well require additional supports. Nevertheless, the essential elements that add up to a good life never change. That's what aging-in-place is all about.



No One Aspires to a Nursing Home – 4 Steps to Reform Elder Care¹

Aldred H. Neufeldt is an international expert on disability policies, programs and practices, and Professor Emeritus in Community Rehabilitation and Disability Studies at the University of Calgary. Aldred has had a long association with Community Living associations and programs at local, regional and national levels. In 1973 he joined Inclusion Canada's (CACL) Roeher Institute (Director from 1975 - 1981) to assist in designing and then implementing the movement's Canada-wide campaign to replace residential institutions with person-centered, comprehensive community-based services. In recent years, he has focused on reform of services and supports for seniors.

It took a rogue virus to make it obvious that 20 or 30 dependent seniors within one area of a long-term care (LTC) facility isn't the best idea in the world. It begs the question of what approaches to long-term care should be considered as alternatives.

Our "nursing home" approach to LTC emerged in the 1960s, a time of great optimism that infirmities of old age could be solved (or at least managed) by the biomedical sciences. Part of that optimism has proven to be justified, part not.

There's little question that biomedical research and medical management has helped maximize health and function in later life. But when it comes to helping people who for physiological or cognitive reasons need help with basic activities of daily life, the picture is very different. It's not the staff – most are good and caring. It's that the 'medical model' they're trained in offers little to ensure meaningful life for people with diminishing physical or

cognitive abilities.

Most everyone knows this. No one *aspires* to go to a "nursing home". People intuitively know that on taking up a 'bed' one gives up deciding when to eat, what to eat (no junk food at age 95?), when to bathe and so on. It's such loss of ability to make decisions on common every-day interests that people resist.

And the more people that live together in a place they can't leave, the more difficult it is to keep an individual's unique interests in focus. Inspired leadership can hold such drift at bay, but with time the drift continues.

Such "total institutions" are dangerous places. Think of the Truth and Reconciliation Commission (TRC) report on Indigenous children in residential schools, or exposés in previous generations of "mental hospitals" and "training schools" as they were euphemistically called.

LTC facilities can't escape such danger, try as they might. Current deaths from COVID-19 are a stark reminder, but we shouldn't forget previous media reports on abuse, neglect, or Westlauffer type murders that continued despite assurances from a succession of public enquiries that "the system is strong – it can be fixed."

I know something of how difficult it will be to change existing LTC into something new. My early career was immersed in replacing large "mental hospitals" with community alternatives, and "training schools" for children and adults with developmental disabilities with individualized community services and supports now in place. Both were resisted by strong interest groups arguing existing systems could be fixed. If we'd contented ourselves with such arguments, thousands of people with any number of disabilities and their families would have been sadly impoverished, as would society.

¹ Parts of this essay were previously published in the *Toronto Star* as an Op Ed on 11/01/21



LTC related interest groups will be no less resistant. When a recent report² by respected thought leaders argues that the solution to LTC problems is to ensure they're all 'non-profit' run, but ignores the inherent loss of choice, independence and control by residents in larger LTC facilities irrespective of who runs them, we know we have a challenge. Like it or not, "total institutions" they are. To change the *status quo* requires a reimagined vision transforming "long-term care" into "networks of caring" that support seniors in living meaningful lives through to death. From prior system transformations we know the following ingredients are essential.

First, focus on the individual. Maximize each person's capacities and compensate for deficits, fostering a sense of success and self-respect. The more seniors can define their ambitions, whilst recognizing their own limitations, the better for everyone.

Second, emphasize flexible resources tailored for the person. Start with

² *Investing in Care, Not Profit – Recommendations to transform long-term care in Ontario*, Canadian Centre for Policy Alternatives, May 21. The orientation of this report contrasts starkly with another published the same time by the London School of Economics titled

Crystallising the Case for Deinstitutionalisation: COVID-19 and the Experiences of Persons with Disabilities which uses a 'rights-based' lens to analyse long-term care.

approaches already successful such as home health care and funding for individuals to hire their own support personnel. They dramatically increase personal satisfaction and decrease demand for "residential beds."

Third, help individuals and small groups develop supports for their LTC needs where they already live. Think, for example, of all the apartment complexes with aging residents preferring to "age in place." Develop policies that encourage sharing the cost of hiring support personnel and nursing assistance as and when required – right where they already live.

Fourth, if congregate LTC-type housing is needed, small and dispersed is good. Encourage development of "community housing" models – each of a size where people can eat and meet around a dining room table. That reduces the risk of exposure to rogue viruses while retaining links with family, friends and others living nearby.

Critics are bound to argue such models aren't cost efficient; but, as a well-known deputy minister once reminded me, that's an argument for the status quo and irrelevant to doing what's best for people.



Community-Based Support – Lifelong

*From an interview by Nicholas Wong, CLO Communications Coordinator, with **Donna Marcaccio**, Executive Director, Rygiel Supports for Community Living*

When discussing what can be done to reform long-term care, it's easy to focus on what we're doing wrong. People who have a disability, many of them young, continue to be dumped in long-term care facilities ill-equipped to meet their needs. Our elders – with and without disabilities – are too often stripped of their autonomy and forced into crowded, potentially dangerous congregate settings.

Yet the future of long-term care may be closer than we imagine: Innovative approaches to aging-in-place are happening all around us, and some have been happening for decades. These examples can give us a glimpse of what's possible and show us the path to get there.

Rygiel Supports for Community Living is one local association whose efforts to provide community-based supports to their residents as they age provides a window into the future. And they've done it by turning to their past for continued inspiration.

Rygiel was founded over 50 years ago as a home for children with multiple disabilities, but soon was influenced by the Principle of Normalization and hence, made the decision to deinstitutionalize and move to a model of small group living. But as the children they supported began to age out of the system, the government started pressuring Rygiel to move them away into institutions. Rygiel refused, and to this day, many of those same children – now adults – continue to be supported by Rygiel.

According to Executive Director Donna Marcaccio, these experiences reinforced

Rygiel's commitment to providing services that are "shaped by the needs and interests of the person" and delivered within the community. "We have to keep the sector's history alive," she says. "It surprises me how many people I talk to don't know the history of institutionalization and that it was the people that we support and their families who taught us what was wrong with that system."

So, when Rygiel faced renewed government pressure, this time to move their older residents into long-term care, they stayed true to their values and stood their ground once again. As a result, they currently support 20 residents over the age of 50 – 7 over the age of 65 – all of whom have complex needs.

How has this approach worked out? Marcaccio points out that they were already capable of managing many issues related to aging due to their familiarity with supporting complex needs. They've also proven that allowing people to age in place can be just as, if not more cost effective than moving them into larger congregate settings. "Whether you lived with two people or fifty people was pretty much the same. It's where the money went that was very different: It didn't go to the individual, it went to the building's maintenance, higher insurance, etc." Marcaccio explains.

In any case, whatever extra support has been required is more than justified by the positive outcomes. The small group living settings and low staff turnover contribute to a much greater atmosphere of familiarity and comfort for residents. "I can't imagine what it would feel like to live in a chaotic environment where you never know who's going to walk into your room today to care for you or how they're going to approach the care," says Marcaccio. Recently, a woman Rygiel had supported for more than 50 years passed away. While it was a sad moment, Marcaccio



takes some comfort knowing that the woman was able to spend her final days at home surrounded by people she was familiar and comfortable with, some of whom she'd known for most of her life.

Asked what others can learn from Rygiel's approach, Marcaccio offers up a guiding question in return:

"If we truly are person-centered and community-based, what does that mean to a person as they move through the lifespan? If we examine that question, I think it paves the way for how we should respond to individuals."



Community Living London Learns to Anticipate Changing Needs as People Age

*From an interview by Nicholas Wong, CLO Communications Coordinator, with **Michelle Palmer**, Executive Director and Aileen Watt, Accommodation Services Manager*

To help people age-in-place, Community Living London (CLL) makes every effort to be as flexible as possible to accommodate people's needs as they get older. One example of this is a specialty home that caters to those with dementia, which can start to manifest in some people with intellectual disabilities as young as their 30s and 40s. CLL's dedication to providing superior and appropriate supports means that these people are able to live out their lives in a real home as opposed to a long-term care institution, where they might end up spending decades.

While some would still characterize small group living homes as "institutional", Executive Director Michelle Palmer disagrees. She explains that a key difference is in attitude, approach and respect. In small shared homes, each person is recognized and appreciated as unique: How they spend their day, what they eat, when they eat and where they hang out (each person has their own room) is determined by the person. "It's not a matter of 'here's your dinner' – it's a matter of 'what do you want for dinner?'," Palmer says. Accommodation Services Manager Aileen Watt provides the example of a Muslim person they support who has his own fridge and a diet that conforms to his cultural and religious beliefs.

Aside from offering increased choice and autonomy, homes offer other distinct advantages over long-term care institutions. People with intellectual

and developmental disabilities can have unique needs that long-term care isn't equipped to support. Unlike staff in a small shared home setting, long-term care staff do not have specialized training to care for people with intellectual and developmental disabilities, nor do they have the time to become familiar with and adequately meet their needs.

However, this is not to say that an age-in-place approach does not come with its own challenges. Staffing ratios are an ever-present issue as agencies strive to deliver the most individualized care possible. Watt also explains that maintaining physical accessibility in their homes has been a struggle, with many being split-level. However, they've worked to combat this issue over the last six years by partnering with investors to acquire homes that have at least some degree of accessibility. This has ensured that people supported are able to remain in their homes for longer and build meaningful relationships with their housemates.

When asked for their advice to other agencies hoping to improve their own age-in-place practices, Palmer and Watt stress the need to anticipate changing needs and prepare ahead of time: Be vigilant for signs of early-onset dementia and make sure your residences are physically equipped to accommodate varying levels of mobility. They also highlight the importance of fostering an organization-wide "commitment and belief that we are a service from birth to death". Ultimately, their goal is to ensure all employees respect and support the people they support with the same standards they would want for themselves – including the ability to age in a place you can truly call home.



A Commitment to Each Person

Maurice Voisin, Executive Director, South-East Grey Support Services

The pandemic we have all experienced over the past year has reaffirmed to me the important role local Associations for Community Living have in supporting people with disabilities in the community. I would like to share the journey we had with a gentleman we supported for over twenty years at our agency – South-East Grey Support Services.

This gentleman was one of the last five residents to leave Oxford Regional Centre (ORC) in Woodstock. ORC was closed in 1996 as part of the Ministry's facility closure plan to repatriate people to the community. Although he and his family were not former residents of our geographical area, our agency agreed to support him as no other agency was interested in developing a plan for him.

There were a few factors that resulted in this person being one of the last residents to leave the facility: he was a physically large man, who sometimes pushed staff and other residents; he was a smoker who was trained in the facility to have only so many cigarettes per hour and he kept staff accountable to that schedule; and he often exhibited repetitive actions that were usually attributed to a mental health condition. Interrupting him during these repetitive actions could result in a number of reactions ranging from a scowl, a loud verbal outburst, the flinging of a plate, invading staff's space or physical aggression.

Our individualized support model was a great fit for this gentleman as he lived in his own apartment in the same home as a staffed apartment in the other part of the house for another person we supported. He had one-to-one staff during the day

and then the staff in the next apartment could respond if there were any issues overnight. Once he left the facility, his medications were reviewed and reduced by a psychiatrist, skilled in consulting with individuals with a dual diagnosis. Staff also learned to give him space when he needed it and implemented the least intrusive method of staff intervention which was very successful. There were no roommates needing to be protected, and we did learn that other residents at ORC had provoked some previous aggression by 'pushing his buttons' at times.

For the first fifteen plus years that we assisted him, things were relatively stable and, other than some staff leaving his team and us needing to repair some damage to the apartment, it was a good match both ways. He then started to develop some health issues and saw the doctor more frequently for some breathing difficulties and other complications. He continued to be comfortable in his own home with a few more support hours until it became necessary for a period of hospitalization for more serious breathing difficulties.

While in hospital, his family doctor suggested to our agency that this gentleman would require more personal support due to the chronic nature of his illness and that his condition would be progressive and there was no cure. The doctor suggested we may need to look at some long-term care options due to the increased level of care. The doctor was able to make a referral for some overnight home care hours upon discharge from the hospital. We continued to support him during the day and home care provided staff overnight as he needed assistance to be physically turned every two hours to reduce bed sores. Home care was able to provide this support for a few weeks and then gave notice that they could not continue, as their support was time limited and linked to the discharge from hospital.



We then went to our agency's Board of Directors for approval for us to finance these overnight additional hours. We also made MCCSS aware of the potential need for fiscal dollars to offset these costs. We continued to provide awake staff from our agency for these overnight shifts in addition to the day-time staff for a number of months. He was admitted back to our local hospital when his condition worsened. His doctor advised that we contact the gentleman's family if they wanted to visit. He passed away peacefully in hospital within the next few days with family, staff, and former staff visiting to say their goodbyes.

His family and many of our staff

commented on how wonderful it was that we were able to provide the increased staff support for him to remain in his own home. We were convinced that an admission or transition to any long-term care facility would have been traumatic and detrimental. We were honoured to have him age in place in his own home and to maintain the relationships he built in his over twenty years with our agency.



Aging in Place is About “Home”

Lisa McNee Baker, Executive Director,
Community Living Ajax Pickering and Whitby

Aging in place. What does it mean? It has a sort of clinical feel to it to me. I asked my 88-year-old mother and 90-year-old father what they thought of the term. And to them aging in place means “staying in your own home with the help you need”. My mother maintains that once you go to long-term care, “it’s all downhill from there!” My mom and dad have lived in the same house for 50 years.

To me, “aging in place” is about home. Being able to stay in one’s home with the appropriate supports in place so that life is good and people are safe and can make decisions about the types of supports they desire/need.

At Community Living Ajax Pickering and Whitby (CLAPW) we strive to help create a sense of home and belonging for the people we support. We see our residential options as a way to provide shelter that is stable, secure, personal, and enduring. We strive to help people stay at home throughout the stages of their lives, tailoring our support levels and our approaches to meet them where they are at.

We recently lost our oldest resident, who turned 100 last May. She had lived in the same house for the past 35 years. Her support needs changed as she aged (as they often do for folks who live to be 100!) and we changed with her. Our staff became so skilled at supporting her and caring for her. The palliative team that was in place the last couple of months of her life were blown away by the level of care and compassion demonstrated by our staff. Yes, she aged in place, but more importantly, she was surrounded by people who knew her so well, had

supported her for years, cared for her deeply and respected her desire to live out her days in the place she had called home for decades.

In February we lost another person we had been supporting for 35 years to cancer. He was able to discuss and make decisions about his treatment options. He was clear about who he wanted to share his diagnosis with and who he was okay talking to about it. He planned for his funeral with staff support and was very clear that he wanted to die in his own bed in his home wearing his favourite pajamas. He was very determined and courageous, as were the staff team that supported him.

As a team, they rose to the challenge of the increased medical procedures that were required and provided him with the support and dignity that he so deserved. In the last week of his life, he asked to go on a drive to the country. He grew up a country boy and wanted to see the place that brought him so much pleasure. The staff team made it happen not just once but twice in the last week of his life. I am sure that this personal and responsive approach would not have happened had he been in the hospital or long-term care.

We sadly are also aware of people with intellectual disabilities that have moved to LTC, some of them quite young. Sometimes this has happened when they move with a parent and sometimes it happens because there just are not any other options available to a person that may be facing homelessness. As an agency, we are committed to doing all we can to prevent the people we support from going to long-term care arrangements. As an agency, we are also committed to exploring how we can support the re-patriation of people with intellectual disabilities from nursing homes to our service.

We did just that recently when a woman who had been in our care years ago before moving to a host family arrangement and



then ultimately ending up in long-term care, returned to our agency to a home where she lives with two other people. Her chosen family remain involved and committed to supporting her in her new home, a lovely three-bedroom bungalow in Ajax.

It is not always perfect in congregate care settings. We know that. But we do our very best and start with the premise that the houses that comprise our residential services are HOME to the people who live there, and this is the most important focus. Yes, it's a workplace, but it is HOME first. I think this approach helps us to keep the focus where it needs to be.

As an agency, CLAPW is excited to continue exploring the notion of "aging in place" and learning from the good people

involved with Seniors for Social Action Ontario (SSAO). We recently had Doug Cartan and Linda Till join a board meeting to share their expertise and perspective on the topic and we are eager to continue the discussion and to continue seeking alternatives to long-term care.



Aging in Place – We Have a Way to Go!

By Tina Williams, Executive Director, Community Living Upper Ottawa Valley

Community Living Upper Ottawa Valley (CLUOV) is committed to sharing practices and processes that relate to success and enhancing people's quality of life. However, we have a way to go before we can celebrate success in supporting seniors in the most dignified and respected manner.

We support some people who are in their 50s, 60s and 70s that live in long-term care facilities or senior's residences. Some are quite content to be there while others would rather be anywhere else. We also support people who are in their 80s who have aged in place with the support of our agency, their families and health supports. We have found that it is important for support to be flexible as the needs of people change as they age. We have supported people through end of life with terminal illnesses and we have been devastated to address emergency health needs only to experience loss.

While we recognize and appreciate the competencies of support teams in LTC, as well as the stress this year has added to their workday, the fact remains that these are institutionalized settings. Some of those we know working in LTC are the exact combination of personality and compassion that I would want in my life, if I could no longer meet my own care needs. Yet LTC facilities as an option for anyone, let alone someone who is not a senior – someone who may have experienced institutionalization in the past and whose only health needs relate directly to their disability – seems like a last resort. The challenge is that some people feel there is safety and continuity in a congregate care setting; that loneliness would not occur; that health needs would be taken care of. Unfortunately, there is no setting that can assure these things. What does create

those safeguards is having relationships. It is so important to have people in one's life who want good things for you, people who are willing to invest the time and energy and even advocacy to help make that happen.

At CLUOV we are trying to address housing needs by seeking community as a first resort. We work with landlords, property owners and municipalities to ensure they recognize their role in providing good housing options, so that we are not the be-all-end-all, by running group homes or tucking people away. We are trying to address poverty by seeking community as a first resort. We work with employers, educators and social services to promote independence and interdependence, and seek ways for people to make contributions to the fabric of our society. We are trying to address health needs by seeking community as a first resort. We help people access in-home support, medical professionals and health promoters so they may age at home with dignity and respect.

When we stop expecting congregate care and segregation in schools, when we support people's choice of where and with whom to live, when we promote and expect inclusion in recreation, employment or social settings, then maybe the people we support will be able to age at home and not in LTC facilities.

We need community partners too. We need eligibility to change so that a disability does not automatically qualify you for a long-term care placement and the life of restrictions that go along with it. We need quality of life to be correlated to each person's definition of it.

The developmental services sector looks to goals and achievements as measurements of the quality of support being provided, the LTC sector attempts to focus on comfort, safety and health. There's a big difference between the two, especially if you have 30 or 40 years left to live.



AFTERWORD

By Judith Sandys and Douglas Cartan

The Community Living movement has long been committed to enabling people with intellectual disabilities to live full, rich lives as an integral part of the community. While the journey to full inclusion is far from over, we have made significant progress. With the closure of the last government-operated facilities in Ontario in March 2009, many assumed that large institutions for people with intellectual disabilities was a thing of the past. But with the arrival of the pandemic, we quickly learned that many thousands of old people – and some who are not so old who have intellectual and other disabilities – are still confined to institutions and that life in these institutions is invariably terrible, creating conditions that are dangerous to the well-being and to the very lives of those confined there.

In these essays, we have asked why, if almost all people say they want to continue to live in their home and community when they are old, do so many (including some who are not very old) end up in these terrible places? We have asked, “what needs to change so that people, regardless of their age or disability, can age in place?” We have asked, “what are some of the alternatives that can be developed?” We have asked, “why are these things not being done?” And we have asked, “what do we need to do to bring about change?”

We hope that, within this very diverse collection of essays, you have found some that have resonated with you, perhaps by providing you with new information, new ideas, or new perspectives. And we hope that these essays have caused you to reflect on why things are the way they are, what needs to change, and what you can do to promote such change.

The partnership formed by Community Living Ontario and Seniors for Social

Action Ontario aims to address the sorely needed reforms for a 21st century eldercare system for all, but especially for those who have a disability. These reforms need your individual and collective action. The required change will not occur without your commitment to make it so.

Current vested interests in the institutional model of care are deeply entrenched and will not change quickly or easily. But we believe that we must make every effort to bring about change and we invite you to be a part of this effort.

What can you do? You can join with others and write to the Premier, to your MPP and to newspapers demanding that we replace the institutional model of eldercare, that we need to develop a comprehensive community-based home and health care support system so that people can age in place as is their choice, and that we need enforcement of effective regulations and standards of care and support.

Change begins with individual action. If you are reading this paper now, consider the action you can take to bring about the reforms that the essays herein point towards. You must stand up and take action now if change is to become a reality.

For more information about ideas, strategies and alternatives check out the SSAO website at <https://www.seniorsactionontario.com/> and review the research and policy papers.