Homes for Life

The Case Against Long Term Care Placement for People Who Have a Developmental Disability

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Preamble

A series of recent news reports, including a report by Canada's military, have documented the extent of abuses in Long Term Care facilities (LTCFs) during the recent Covid-19 pandemic (TVO, 2020).

The story they have not told is that of the decades of abusive and neglectful conditions that have been pervasive in these institutions, but multiple other reports over the years have been explicit in this regard (Crawford, 2007; Crawley, 2020b; Dubinsky, 2018; O'Keefe, 2018; Ombudsman, 2016; Pedersen et al, 2018; Wettlaufer Inquiry, 2019; Sourtzis & Bandera, 2015).

In 2006, the Ministry of Community & Social Services and the Ministry of Health, introduced a *Long Term Care Access Protocol For Adults With A Developmental Disability*. It laid the groundwork for individuals, some as young as 21, to be placed in long term care institutions. Today guidelines for achieving the institutionalization or re-institutionalization of individuals with developmental disabilities in long term care facilities are still in place (MCSS, 2018).

This policy signalled a return to the policies of medicalization and institutionalization that had led to the development of the hospital schools like Huronia in Orillia throughout the early part of the 20th century. Services were moved from the Ministry of Health to the Ministry of Community and Social Services in 1974 to facilitate community living after the Williston and Welch reports (MCCSS, 2018).

Unfortunately about 500 children were left behind in privately operated nursing homes when the transfer or public institutions occurred. Many of these children were found years later in the early 1980's by staff of what was then the Ontario Association for The Mentally Retarded. These children were suffering malnutrition, dehydration, hypothermia, and a range of other medical conditions related to the poor care that they

were receiving in these institutions (Hansard, February 18, 1983). The Hon. Larry Grossman introduced the *Health Facilities Special Orders Act* to take over one particularly bad facility, Ark Eden in Stroud, Ontario, where several children had died of severe neglect.

The 2006 Protocol was a reversal of what had been won decades earlier by re-institutionalizing individuals with developmental disabilities.

Many people with developmental disabilities who have been institutionalized have suffered trauma as a result. Having to enter a long term care institution once again because of aging would be devastating for them.

It is no less devastating for those who have never been previously institutionalized. Testimony in the 2016 *Ian Cole Human Rights* case illustrated the harm experienced by people with Developmental Disabilities as a result of institutionalization (Ontario Human Rights Commission, 2016). The underlying concerns about care in long term care facilities is often exacerbated for such individuals by virtue of their learning challenges, their perceived differences, and the frequent devaluing and inappropriate responses or treatment they experience. As a result, it was clearly recognized that the best option would be to assist them to age in place in a home of their own, with the appropriate supports to enable them to do so.

The decision in the *Cole* Human Rights case removed arbitrary limits on home care as set by policy, referring to these limits as discriminatory. Instead, Local Health Integration Networks (LHIN) supports were to be driven by individuals' needs, even if that care exceeded previously provided limits. Keeping people out of long term care facilities was a fundamental tenet of this Human Rights decision, and the advice of the subsequently established Ministry of Health Task Force charged with developing implementation guidelines related to that decision.

Any LHIN's suggesting that this tenet was unique to the Cole decision are incorrect. This was a decision that can be generalized to all individuals with developmental disabilities who have complex medical needs, and quite probably could be generalized to any person with complex medical needs.

Are Long Term Care Facilities A Viable Option?

Those not familiar with what levels of care can actually be expected in long term care facilities may believe that these are specialized facilities that can provide care that cannot be provided in the community. Some of the types of care that may trigger consideration of placement into a LTCF, and which are believed to be provided in LTCFs include:

- Certain medications, including injections, narcotics and end-of-life meds
- Tube feeding and medication admin via tube
- Skin/wound care
- Specialized nutritional needs
- Oxygen
- Respiratory treatments, such as chest physio (percussion/compressions/vibrations) and nebulizer treatments
- Catheterization
- Suctioning, including deep suctioning
- PICC Line management
- Tracheostomy care
- Ventilator support
- Intubation

Other triggers, not specifically medically related include:

- Pain
- Mobility impairment
- Dementia behaviour support, especially wandering, escalating confusion, sundowning, confabulation and aggression.

In fact, many of these procedures are not delivered in long term care facilities, or if delivered, may not be done optimally.

As author of this position paper, I bring a number of perspectives and background to this discussion. I was a former provincial advisor with Community Living Ontario in the 1980's and mother to Becky Till, a young woman with very complex medical needs whom I adopted after she almost starved to death in the Jann Lynn Nursing Home in Keswick, and subsequently experienced severe internal damage to most of her organs,

resulting in life-long major medical complications. I was appointed to the Ministry of Health Advisory Group that was struck after the Ian Cole Human Rights case. My expertise was valued because of my having successfully maintained Becky at home for decades in spite of the complexity of her health needs, along with my related training, and the extensive knowledge I had acquired as a consultant for others with complex medical needs.

I want to provide the following information that may be helpful to Executive Directors of Association's for Community Living (ACL) and other community agencies in the current climate;

- None of the medical interventions described above require LTC placement. One procedure listed above - intubation - requires emergency hospital level care, and could not be done in any other type of facility. However, subsequent ongoing tracheostomy and/or ventilator support can be managed outside of hospital or other medical facility, and indeed is being done in community for many individuals.
- LTCFs have, historically, failed to deliver these kinds of medical interventions correctly or reliably because they rely heavily on Personal Support Workers (PSW's) who lack the skill to perform them, and training is often not provided to enable such skill development.
- Registered Practical Nurses (RPNs) and Registered Nurses (RNs) are at a premium in LTCFs, since PSW's are often hired instead at less cost. RNs and RPNs are often also in short supply in terms of availability, and many shifts which should be filled by someone with these qualifications are not filled. Many LTCFs may have upwards of 100 individuals being supported by an RN if one is present for a shift.
- Many LTCFs refuse admission to people who require this level of care, or if they accept the individual, the actual provision of care may be significantly sub-optimal or even completely lacking.
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What Is The Alternative?

Most of the tasks listed above can be done by either a DSW or PSW working within an ACL setting. If the staff person lacks the training/certification necessary to perform

specific procedures, a qualified professional, such as an R.N or Respiratory Therapist can train and delegate a staff person to do so provided that the professional maintains some level of ongoing responsibility for supervision. This is authorized under the Controlled Acts legislation and there is online guidance (Power point) concerning this – Developmental Service Providers and the Regulated Health Professions Act - http://www.community-networks.ca/wp-content/uploads/2015/07/April-24-2013-DS-and-RHPA-Final.pdf

Agencies often sign an agreement with the training/supervising Professional, specifying the details of the circumstances of this delegation. Nurses or other professionals can be from the Local Health Integration Network (LHIN) or, when these are replaced, from the Family Health Teams or anyone else who can maintain these obligations.

Some of the tasks listed above may require an RPN or RN to perform them, and this is often available through the LHIN visiting nursing services. People living in agency supported settings are fully eligible for all LHIN supports, although LHIN response does vary across the province.

Specifics Concerning These Procedures

- Medication administration is commonly performed in agency settings, but more unusual medications or medication routes may be more challenging. Narcotics require locked arrangements with signing provisions, injections may need to be done by a visiting nurse (but in some situations can be delegated when training is provided), nebulizer Meds are easily learned, instillations and flushes (such as those via catheter) can be done by visiting nurses, topical pain patches and rectal meds such as rescue seizure meds are easily learned and can be administered by agency staff with training as needed.
- Tube feeding and medication administration are not overly complex procedures, and can easily be learned and managed safely by agency staff.
- Skin care and wound care can be managed in community settings, and visiting wound care Nurses are available for challenging situations. It should be noted that pressure ulcers and infected wounds are often found in LTC residents, and this is one of the findings noted in this spring's military report. They typically develop when an individual is not repositioned frequently enough to avoid wound development. Specialized seating and sleeping surfaces are available and can be put in place in community settings to assist in preventing or managing such challenges.

- Nutritional needs may change with aging, and Nutritional consultation is a service available through the LHINs. Supplemental oral and tube feeding solutions are available to help meet nutritional requirements. Specialized diets, such as blended, puréed, or thickened options are available for purchase or can be made on site with relatively little difficulty.
- There are oxygen devices now that draw oxygen directly from the air and are much simpler to use than the old oxygen tanks. Many oxygen supplies are funded from a specific Respiratory Supplies fund through the Ministry of Health Assistive Devices Program - https://www.ontario.ca/page/respiratory-equipment-and-supplies Oxygen can safely and readily be provided in community settings, and portability is easily accomplished, enabling the user to move about settings outside of their home.
- Respiratory therapists are also available in most communities to assess oxygen level requirements and can assist in obtaining and demonstrating use of this equipment. They can also provide ongoing advice and guidance as well as intermittent re-assessment. Respiratory therapy is a readily learnable skill, and can and should be done in a person's own home by agency staff, who can most readily meet the frequency and timing requirements of the procedure.
- Oxygen monitors are also easily obtainable to provide intermittent or ongoing measurements of a person's oxygen level requirements.
- Catheterization is a procedure that is learnable….in fact children who require intermittent catheterization may be taught to self-insert and manage their own catheterization.
  In-dwelling catheters need attention in order to minimize the risk of acquired Urinary Tract Infections, and this is training a nurse can provide. For those who require long-term catheterization, but where access is difficult physiologically or behaviourally, a minor surgical procedure called a supra-pubic catheter can be considered in order to establish alternate and easier to manage access.
- Most individuals requiring suctioning do not need deep suctioning, and this is something that is generally not done in a LTC facility correctly or reliably. Regular suctioning is a skill that a DSW or PSW can be delegated to perform with training and under R.N. supervision. Please note that choking was one of the issues identified in the military report with respect to LTCFs, and aspiration is a regular hazard in these facilities, especially those that are understaffed or have low staff to resident ratios, thus LTC placement is not a reliable means of ensuring this type of care.
- Individuals requiring deep suctioning are also unlikely to be accepted by a LTCF since they would likely rely on R.N.'s to perform the procedure and R.N.'s are not always available in these facilities.

- Suctioning, including deep suctioning is done routinely in family homes for children with this level of need, by both parents as well as support personnel. This is evidence that it is a trainable and transferable skill that can be delegated if the commitment to “age in place” and proper training is available.
- Supporting an individual who has a PICC Line (a form of long term intravenous access) is manageable in agency settings, but infusions through the PICC line need to be set up by an RN, or an RPN with related certification. Once a PICC line infusion is set up, the ongoing infusion is managed by a pre-programmed portable pump, and is routinely done in community settings for many people.
- Tracheostomy care is another skill that can be learned and delegated to agency staff. It is another skill often managed by families in their own homes, another indicator of the feasibility of learning and managing this type of care.
- Ventilator support is a more challenging level of care, but is also care which is currently managed in family homes, and could be managed in an agency supported setting. Additional nursing visits and Respiratory Therapist involvement would be helpful.
- Pain management can be challenging, but pain clinics exist throughout the province to help people manage complex pain and these resources are available to people living in agency supported settings. Pain med admin may require additional training or secure practices, but remains viable in any setting. Pain can exacerbate behaviours that are difficult to manage, but adequate pain control greatly helps address this challenge. Behaviour therapists can assist in developing appropriate protocols for supporting an individual in such circumstances.
- Mobility impairments may emerge as an individual ages, and agencies should be encouraged to plan in advance to ensure their settings are modified, or supplied with adaptive aids as needed. Stair and porch lifts; Hoyer or ceiling lifts for transfers; accessible washrooms, hallways and doorways; handrails throughout the home; specialized positioning aids; beds that can be raised or lowered; and elevated bathtubs or wheel-in showers are just some of the options available to assist in this regard.
- Dementia related supports are often required, especially for wandering, confusion, and sundowning, and these may take the form of ensuring outdoor areas are fenced, doors can be safely secured, and staff are trained in managing confusion or memory loss. The Alzheimer’s Society regularly provides a multitude of resources and programs related to Dementia supports. Dementia response in many LTCFs often take the form of medications which may be excessive for the individual, such as the anti-psychotic drug Haldol, even in the face of no psychosis. Other sedating drugs may be used to quiet or suppress a resident. This approach is referred to as using a chemical straight jacket. Medications may be of value, but need to be meeting the individuals needs, not over-controlling. LTCFs

also rely heavily on locked rooms or wards, and individuals may spend their entire time in those locked settings without opportunity to ever go elsewhere, as the LTCF seldom assigns staff support to escort a resident anywhere.

- Ministry and Agency efforts to mitigate the negative aspects of LTC placement for an individual with a developmental disability have limited capability of actually minimizing the harm of the placement. Institutions cannot be fixed. They are simply harmful, and there is ample evidence of this fact. Putting additional staff support into an LTC setting can not undo the trauma of the move, the devaluing that permeates, the congregate practices that predominate, the violence that is frequent, the depersonalization and isolation which is pervasive, the loss of dignity, and the loss of normative life experiences. Additionally, agencies that have experience with this practice often report that the regular personnel in the LTCF, from admin down to front line staff, do not see the individual with a developmental disability who has external supports as their responsibility. Rather, the LTCF personnel leave the care to the agency support person(s), believing that the person is the responsibility of the agency. This leaves the person quite abandoned within that setting for any time that his/her agency support person is not present.

What Resources Can Be Obtained to Support People Aging in Place?

- LHIN's (or family health teams) and sometimes hospitals, are in a position to provide R.N.'s, R.P.N.'s, P.S.W.'s, Nutritionists, Physiotherapists, Occupational Therapists or Respiratory Therapists to support people requiring specific medical or paramedical care in a community living setting, including group homes and Supported Independent Living (SIL) programs as well as Family Homes, even if they are agency supported and staffed. BDACI in Brockville, L'Arche Daybreak in Richmond Hill, and Rygiel Supports for Community Living in Hamilton are examples of some locations that are using LHIN resources to provide injections, catheterization, PSW support, physio and occupational therapy, speech and language/swallowing assessments and consultation, and nutrition assessments and planning, amongst other supports.

- Executive Directors may be concerned about MCSS reluctance in hiring nurses. L'Arche Daybreak hired a Health Services Coordinator (who happened to be a nurse), who works fulltime onsite. Ongoing discussions with MCSS regarding strategies to explore and establish a Homes For Life approach would be strategically wise at this point, especially given the mounting awareness of the abysmal conditions in so many LTCFs.

Summary

Resources do exist to ensure that individuals with developmental disabilities at risk of institutionalization in LTC facilities are, instead, able to age in place. Advocacy may be required by both local and the provincial associations to ensure some degree of uniformity of approach across the province regarding both LHIN resources and MCSS support, especially with the introduction of the new family health teams. It is hoped that this information will be helpful to ACL's and other community agencies in their ongoing support of individuals. For more information, I can be reached at: linda.till@rogers.com

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