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ALTERNATIVES TO INSTITUTIONS SERIES

DENMARK - THE GOLD STANDARD IN LONG TERM CARE: HOW DENMARK'S APPROACH IS DIFFERENT FROM ONTARIO'S

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Canada, and specifically Ontario, are light years behind Denmark when it comes to long term care philosophy, policy, and practices. In this report the differences between the two jurisdictions are compared with a view to concluding how Ontario could be learning from Denmark and implementing some of its more progressive practices.

The Demographics

Denmark has a population of just over 6 million people.

If we add together the populations of Ontario's largest cities and towns – Sudbury, Toronto, Ottawa, Mississauga, Markham, Kingston, Windsor, London, Niagara Falls, and Thunder Bay, their combined populations are also just over 6 million people.

If Ontario were to choose to launch pilot projects based on philosophies, policies, and practices pioneered in Denmark in its largest towns, cities and regions, these initiatives could be expanded through Regional Offices across Ontario.

Denmark's 65+ population was 19.91% (1,168,571) of the general population in 2020[1]. Ontario had 2,504,358 seniors 65+[2] out of a total population of 14.711 million [3] in 2020, or approximately 17%.

Denmark's population is older than Ontario's but its rates of institutionalization are far lower than Ontario's. Ontario has approximately 78,000 long term care beds with a government commitment to add 30,000 more (Izenberg et al, 2018). Denmark has a total of 14,076 beds designated Curative Care (13,659), Rehabilitative (168) or Long Term Care (250). [4]

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[1] Please see https://www.indexmundi.com/denmark/demographics_profile.html

[2] Please see https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1710000501&pickMembers%5B0%5D=1.7&pickMembers%5B1%5D=2.1&cubeTimeFrame.startYear=2016&cubeTimeFrame.endYear=2020&referencePeriods=20160101%2C20200101

[3] Please see https://www.ontario.ca/page/ontario-demographic-quarterly-highlights-first-quarter-2020

[4] Please see Page 2 https://ec.europa.eu/eurostat/statistics-explained/pdfscache/37387.pdf

This means that Ontario's rate of institutionalization of older adults over 65 is currently 3.1% set to rise to 4.3% with the addition of 30,000 new institutional beds. Institutionalization is literally the worst approach for caring for older adults and people with disabilities (Laucius, 2021; Ottawa Citizen Editorial Board, March 24, 2021).

Denmark's rate of institutionalization is 1.2%

Ontario institutionalizes older adults at an almost three times higher rate than Denmark. So, what is the difference? How is Denmark keeping people out of institutions while Ontario is institutionalizing people in the tens of thousands?

HALLMARKS OF DENMARK'S SYSTEM OF LONG-TERM CARE VS ONTARIO'S

Core Legislated Principles Are Different

Increase Quality of Life and Stress Independence

Denmark's policy and programming approach is clear. It aims to increase quality of life for older adults and their ability to take care of themselves, while remaining as independent as possible (European Commission, 2018). Ontario's approach does not promote quality of life, but emphasizes rationing of care, and there is little to no emphasis on rehabilitation.

Empower Service Recipients

Denmark's Health Law has a distinct prevention focus, and promotes the integration of services, access to information, transparency, and short wait lists (The Commonwealth Fund, 2020).

The Social Services Act incorporates a right by service users to influence social service provision, ensures decentralized services, and prohibits monopolies requiring municipalities to choose any private operators according to quality and price (WHO, 2019:3).

National quality goals include enhancement of patient engagement as an objective. "Regarding long-term care, the quality of user satisfaction is collected every two years from a representative sample of beneficiaries 67 years of age or older. Between 2009 and 2015, 2286 interviews were carried out with older individuals who received home help in their own homes or in nursing homes.

Data on patient experience are used to inform activities related to providers' inspection, regulation, and accreditation. These data are also used to provide feedback to practitioners and to inform quality assurance. Data on beneficiary experience are collected via national surveys or provided directly by the beneficiary in their medical records through the sundhed.dk portal" (WHO, 2019: 19).

Those who receive services as well as their organizations are involved in policy making at the Federal, Regional, and Municipal levels (The Commonwealth Fund, 2020).

In sharp contrast, Ontario has no prevention focus, does not integrate long term care services, limits access to information and transparency concerning quality, has long waiting lists, and has a former nursing home senior executive serve on two important planning and quality assurance bodies – Ontario Health and Health Quality Ontario[5]. Ontario Health is responsible for the majority of health planning taking place in Ontario, but has no representatives of long-term care consumers, their families, or advocates, although it does have one "hospital patient turned entrepreneur".[6] It does have representatives from the corporate financial, manufacturing, information technology, and transportation sectors as well as the health care and military sectors.

Service users and their advocates have no representatives on important planning and quality bodies, and have literally no say in policy decisions. In fact, their attempts to influence government are often ignored and louder voices of corporate long term care representatives and their lobbyists and union lobbyists drown out the voices of older adults themselves.[7]

The Ontario government does not collect feedback from residents of long-term care facilities or those receiving home care and place it in a publicly available provincial database, and in the absence of any data there is no consumer-directed information to inform which facilities need to receive more stringent inspections. In fact, long term care facilities with few complaints are more likely to get comprehensive inspections than problematic facilities, according to testimony by a manager of the Inspection Branch to the COVID-19 Long Term Care Commission.[8]

A Service Philosophy Based Upon Deinstitutionalization and Reablement

In the 1970's Denmark embarked upon a policy of deinstitutionalization finally resulting in a legal ban on constructing institutions in 1984. It chose instead to rely on community-based care. It phased out large institutions with multiple beds in each room and facilities that resembled hospital environments. These were replaced with individual living spaces to ensure privacy and control. Those who live in these environments are considered tenants not residents, and individuals can choose to continue to live with a spouse. Wait times do not exceed two months and tenants have a free choice of residential provider. For-profit

[5] Please see Shelly Jamieson – Health Quality Ontario https://www.hqontario.ca/about-us/our-mandate-and-our-people/board-of-directors-and-committees/shelly-jamieson and Ontario Health https://www.ontariohealth.ca/our-team/board-directors Ms Jamieson is the former President of Extendicare and Executive Director of the Ontario Nursing Home Association (now the Ontario Long Term Care Association) the lobby group for institutional long term care providers.

[6] Please see Jackie Moss https://www.ontariohealth.ca/our-team/board-directors

[7] Please see SSAO How Vested Interests In Long Term Care Maintain The Current System https://d5bb3c6f-31a3-47ef-a85b-5c06ab03f844.filesusr.com/ugd/50033d_2c9a10ded77b450cb487c106a69b3579.pdf

[8] Please see testimony of Pamela Chou to COVID-19 Long Term Care Commission Pg. 50/51 September 15, 2020 http://www.ltccommission-commissionsld.ca/transcripts/pdf/GovOntario_MLTC_LongTermCareInspections_Transcript_September_15_2020.pdf

involvement remains marginal. Tenants decide what services and activities they wish to be involved with, and agree to pay rent and for meals and private expenses out of their pensions.

Nursing and other types of care are free of charge. Under pressure from the Danish Alzheimer Association alternative approaches that foster self-determination and self-reliance have been introduced. To bridge intergenerational divisions, students and older adults are often housed in the same buildings to create a village concept (WHO, 2019: 32).

Two thirds of older adults requiring long term care receive it in their own homes. More recently, reablement philosophy has guided Denmark's approach to long term care and in January 2015 new legislation mandating that all municipalities consider whether someone could benefit from reablement services came into effect. It "emphasizes a user-centered, preventive and proactive approach to care by working towards maintaining and regaining the skills older people need to continue to live independently" (WHO, 2019:3, 4). It is offered through a 12 week exercise training course where older adults work with multi-disciplinary care providers to meet specific activities of daily living goals (i.e. showering, basic home cleaning etc.). Those who are unable to gain from a reablement approach to function independently receive in-home assistance (WHO, 2019: 26).

Ontario has gone in exactly the opposite direction, relying on building more institutional beds and redeveloping others, using a custodial congregate care system.[9] This is the government's idea of "modernization." Little if any attention is paid to "reablement" and to maintaining people in their own homes and communities. This has resulted in the often unnecessary and unjustifiable institutionalization of 78,000 people in predominantly privately-operated facilities with the Ford government planning to build 30,000 more institutional long term care beds.[10]

Denmark Emphasizes Care at Home

Denmark spends about 1.2% of its Gross Domestic Product (GDP) on home-based services – more than half of its overall spending for long term care, making care at home a policy priority. This was part of an integrated care system with an emphasis on home and community-based long term care, meaning that one organization cared for all elders requiring long term care in a district. This resulted in Denmark having fewer older adults living in long term care institutions than any other European country, and no new long term care facilities having been constructed since 1987. Instead, Denmark focused on construction of a wide range of different types of dwellings for older adults. Consequently, the number of residents in long term care facilities

[9] "The Ontario government has allocated 11,707 safe, modern long-term care spaces to be built through 80 projects across the province. These projects include building 7,510 new spaces and 4,197 upgraded spaces. Of the 80 projects, more than 60 involve the construction of brand-new buildings and 35 involve campuses of care where multiple services will be provided on the same site." https://news.ontario.ca/en/backgrounder/60794/ontario-adding-and-upgrading-long-term-care-spaces-across-the-province

[10] "**Ontario** is investing $1.75 billion to create **30,000 beds** over ten years. Today's announcement brings the total number of new and upgraded **long-term care** spaces in the pipeline to 22,368. As of June 2020, **more** than 38,500 people are on the waitlist to access a **long-term care bed**." https://news.ontario.ca/en/release/59292/ontario-adding-3000-new-and-upgraded-long-term-care-spaces

fell from 51,000 in 1987 to 31,500 in 2003 (Business & Health Administration Association, 2017:226; Statistics Denmark, 2005).

Denmark has a policy that requires that people remain at home as long as possible with the support of an extensive municipally-organized in-home care program. Doctors refer their patients for home nursing at no cost with some subsidized additional care that is means tested (WHO, 2019).

Denmark's comprehensive in-home nursing services are available 24/7 free of charge with co-payments only above designated income levels for additional services. These generally involve assistance with activities of daily living, personal care, and food service, as well as home adaptations and medication and nursing supplies based on need. Home nursing services are organized for individuals after acute illness and for those who are chronically or terminally ill in order to avoid institutionalization. Individuals and families may choose their preferred provider of these services and only accredited companies may provide these and additional services (WHO, 2019: 31).

It is this intensive approach to in-home assistance that appears to have caused a drop in the proportion of citizens over 75 needing to live in protected housing and long term care facilities from 15% to 13% between 2010 and 2015 (The Commonwealth Fund, 2020).

Only about 9% of family members have been found to provide personal care (The Commonwealth Fund, 2020).

There has been a reduction in for-profit provision of home care since 2013 because of a change in legislation intended to increase real competition among providers and reduce their number to allow more manageable choice by consumers. This resulted in for-profit providers lowering their prices and ending up bankrupt. The Danish government has now taken steps to reduce the number of bankruptcies and ensure continuity of care for beneficiaries (WHO, 2019: 34) .

Denmark also offers day centres that provide social and educational activities – language courses, day trips, social and cultural events (WHO, 2019: 33).

Ontario's policy is diametrically opposed to this. In Ontario, home care is stringently rationed, complicated, and caps are placed on the number of hours per week individuals may have (Grant & Church, 2015). It is overly bureaucratic and allows care providers to bid on which families they wish to serve or not. Ontario's funding for home care is also woefully inadequate compared to the billions it invests in institutional care. Consequently, people follow the money into institutions, rather than receiving intensive in-home care tied to their needs. Home Care Ontario has stated "Even before factoring in the demographic challenges of the future, today's home care system is underfunded and stretched too thin. This underfunding is exacerbated by structural issues such as growing demand, and recent policy changes that drive the cost of delivery higher. Because of these financial pressures, the system now finds itself 'rationing care' which ultimately is putting other areas of our health care system under greater strain" (Home Care Ontario, 2018).

Denmark Has a Paid Family Caregiver Program

Compared to most other countries, Denmark relies less on unpaid caregiving, especially by women. Respite services are more readily available for a few hours per week to several days and are organized either in-home or in a facility, and delivered by municipalities. (WHO, 2019: 25).

Training and support (Learn To Cope Program) are also offered, and the National Dementia Action Plan has funded 13 counseling centres for people with dementia with the Danish Health Authority, allocating funding for respite services (WHO, 2019: 25).

There has been an increased emphasis on women taking part in the labour market. "A key measure to achieve this goal was transforming unpaid care work into paid employment" (WHO, 2019: 14). Consequently unpaid caregivers tend not to report difficulties in attempting to reconcile work and caregiving (Rodrigues et al, 2013).

There is a range of services available to unpaid family caregivers, and caregivers can also request to become a paid caregiver for a family member. If a municipality decides that the only alternative is outside the home care, or hiring a full-time caregiver, then the municipality will provide a prescribed salary based on national yearly income for up to six months. Municipalities also compensate caregivers for lost earnings if they are caring for a relative with a terminal illness (WHO, 2019: 25).

In Ontario, caregivers receive extraordinarily little assistance, and respite is generally provided in institutions with some assistance through day programs and minimal in-home assistance.

Many caregivers prefer not to use facility-based respite unless exhaustion forces them to, seeing it as a gateway into an institution.

Caregivers are not paid and receive few benefits and little assistance from a rationed home care system. However, they are allowed to take leaves from employment if a medical professional issues a certificate stating that the person they are caring for has "a serious medical condition with a significant risk of death occurring within a period of 26 weeks" - a rather gruesome criteria for support of caregivers.[11]

Non-Profits Act As Advocates

Rather than providing direct services, several non-profit organizations in Denmark play an advocacy role, while others such as DaneAge advocate for older adults' rights and well-being, and the Danish Alzheimer's Association organizes self and peer support activities (WHO, 2019:15).

[11] Please see Family Medical Leave https://www.ontario.ca/document/your-guide-employment-standards-act/family-medical-leave

In Ontario, non-profits deliver services and generally do not engage in advocacy with government. To do so would place them in a conflict of interest since government funds them.

A particularly disturbing development in Ontario recently from the perspective of bereaved families, had non-profits supporting a government law to raise the bar to gross negligence to prevent lawsuits for simple negligence. This meant that bereaved families that had filed lawsuits against long term care facilities where their loved ones died had to meet a higher standard in seeking justice. Many families felt that non-profits were placing their own interests above those they served by supporting the government in this. [12] While SSAO understands that non-profits have insurance concerns, these and other service-related issues are what prevent them from taking strong advocacy positions shoulder to shoulder with the people they serve.

Some organizations that would normally have been advocates for individuals, especially those living in long term care, have taken funding from long term care corporations, thereby placing themselves in conflict of interest as advocates. Extendicare corporation, for example, is "in partnership" with the Alzheimer's Society of Canada (Extendicare, n.d.) Extendicare Assist managed the Orchard Villa long term care facility in Pickering where over 70 residents died in the first COVID wave, and families have launched lawsuits and asked for a criminal investigation (Rocca, 2020). It was also the subject of a damning military report.

Chartwell, a private corporation that has many nursing homes across Canada, has also supported Osteoporosis Canada, the Canadian Diabetes Association, and the Alzheimer Society (Chartwell, n.d.).

Denmark's Long Term Care System Is Decentralized

Denmark has a universal, decentralized health system whereby its Federal government provides block grants from tax revenues in an 80/20 cost sharing arrangement, to five democratically elected regional councils and 98 municipalities. Long term care is funded under this system, meaning that there is a high degree of local decision making and input into how care is delivered (The Commonwealth Fund, 2020).

Long term and chronic care responsibilities are "shared between hospitals, general practitioners (GPs), and providers of municipal institutional and home-based services." (The Commonwealth Fund, 2020) GPs provide medical follow-up to individuals with chronic care

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[12] ONN refers to the Ontario Non-Profit Network. "ONN supports liability protection outlined in Schedule 1, Supporting Ontario's Recovery Act, 2020 only. ONN has been calling for liability protection for nonprofits and charities since June 2020, including in our Fall 2020 budget submission. ONN is pleased to see that the provisions are retroactive to March 17, 2020. It is important to note that liability protection only applies to those organizations that follow all public health guidelines and operate in "good faith". Negligence or abuse and bad actors will not be protected by this liability coverage. This liability protection only covers the inadvertent transmission of COVID-19, and no other issues." https://theonn.ca/ontario-nonprofits-call-to-action-call-and-email-your-mpp/

needs, and municipalities plan, fund, and deliver both care and assisted living support at home, or in municipal institutions, based upon need (The Commonwealth Fund, 2020).

Ontario's system is top down. Towns and cities have no say in whether or not a long term care institution is built in their area if the provincial government decides to award beds there. The government makes the announcement, and the local Mayor is expected to be there (Office of the Premier, 2020). Sometimes the government just issues a Ministerial Zoning Order that overrides any local concerns and proceeds over municipal objections (Queen, 2021).

General Practitioners Not Hospitals Make Referrals for Assistance

In Denmark general practitioners play a significant role in helping people to access in-home support and other assistance. They refer to a social worker who initiates intake, and hospital patients are referred back to their general practitioners, who receive discharge summaries and follow up with their patients. Those discharged from hospitals can also receive follow-up home visits from GPs or nurses one week from discharge, which can be repeated several times, to ensure that individuals receive the follow-up support they require (WHO, 2019: 27).

In Ontario, general practitioners have little involvement in post-hospital discharge planning and rarely conduct in-home visits to patients. This is all done through hospital discharge planners, often in conjunction with local health integration networks. None of these planners know the patient as well as a general practitioner might, but are charged with post-discharge planning.

Individuals and families are often just asked to choose from a list of possible long term care institutions, and accept the first bed that becomes available, especially if heavily rationed home care is not available, or able to provide enough in-home assistance.

Institutional Services Are Predominantly Not For Profit and Emphasize Privacy and Control by "Tenants"

More than 90% of Denmark's long term care institutions are public, and therefore non-profit (The Commonwealth Fund, 2020).

Residential services are built to different design standards, and those who reside there are considered tenants not residents. Tenants live in their own units with kitchenettes, a washroom, living room, and bedroom.

Placing people in long term care generally does not happen unless they require more than 20 hours of care per day according to Tine Rostgaard, a professor at Roskilde University. She also says there is one care worker for every 2.5 residents in the daytime (Nuttall, 2021). Cooking aromas, open concept kitchens, herb and vegetable gardens, restaurants open to the public and libraries are common features of "nursing homes" in Denmark because food is considered medicine, and tenants are expected to remain as active, independent, engaged, and healthy as possible (Canadian Frailty Network, n.d.).

In Ontario, approximately 60% of long term care institutions are operated for profit, and some non-profits have also contracted out their management to for-profit companies like UniversalCare with spotty track records (Wallace, 2020).

Ontario nursing homes lack privacy, residents' lives are subject to routinization and assembly line custodial care. There is a lack of emphasis on healthy living, good food, and resident participation in cooking, gardening, and other activities of daily living. They are generally treated as passive recipients of care, living up to their labels of "high acuity".

Most facilities have not been able to meet basic legislated standards (Pedersen et al, 2020). Nevertheless the companies that run them made significant payouts to shareholders and seniors executives (Lancaster, 2020; Wallace et al, 2020; Milstead, 2021).

National Government Sets Standards

Denmark's Federal government is responsible for the regulatory framework for all health services, planning, monitoring care quality, and licensing of professionals. Funding is allocated to regions and municipalities according to sociodemographic criteria (The Commonwealth Fund, 2020).

In Canada, the Federal government plays a very minor role in setting and enforcing standards and leaves this up to the provinces.

In Ontario, the Inspection Branch has been weak, generally not invoking sanctions even for facilities' repeated flaunting of the Act (Pedersen et al, 2020).

Funding is not allocated according to performance standards. Instead, some facilities with the worst records have received funding to build even more beds (Payne, 2020).

Analysis

This report has outlined the myriad ways that Ontario's long term care system differs from Denmark's, and identified areas where changes might result in significant improvement.

This is especially true with respect to the philosophy underpinning long term care in both jurisdictions, the need for decentralization, and a much heavier emphasis on in-home and community care.

Ontario could benefit greatly from studying Denmark's system, reducing its own reliance on an unsustainable, outdated institutional approach, and building in empowerment processes for recipients of long term care services and their loved ones.

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