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A CALL TO END INSTITUTIONALIZATION VS INVESTING MORE FUNDING IN INSTITUTIONS AND MAKING THEM NON-PROFIT

A TALE OF TWO REPORTS

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Last month a new report was issued by the London School of Economics, Crystallizing the Case For Deinstitutionalization: COVID-19 and the Experiences of Persons With Disabilities[1] that stands in sharp contrast to a report by the Canadian Centre for Policy Alternatives Investing in Care Not Profit: Recommendations to Transform Long Term Care In Ontario[2].

The two reports could not be more different in perspective.

The London School of Economics (LSE) report recommends the need for deinstitutionalization asserting that institutions, founded on ageist and ableist belief systems that have prejudice at their core, are an inappropriate way to care for people with disabilities and older adults.

The Centre for Policy Alternatives (CPA) report recommends ways to attempt to improve institutions, presumably maintaining them to house older adults and people with disabilities, but make them non-profit.

The LSE report seems to support SSAO's position that it is a prejudicial belief system that results in the segregation and exclusion of devalued people from mainstream society – one that supports their mass institutionalization, rather than advocating for their stated preference to live at home or in the community.

This same belief system also keeps advocacy groups and unions from finding common cause to promote a non-profit, community-based system of care that would better support everyone, including retired union members.

Because the Ontario public has not been exposed to innovative, community-based alternative models of caring for older adults with complex needs that exist for other groups and in other jurisdictions, the view that some will always need an institution persists. There is little understanding of the impact of institutionalization on those subjected to it.

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[1] See the London School of Economics report here: https://www.lse.ac.uk/cpec/assets/documents/CPEC-Covid-Desinstitutionalisation.pdf

[2] See The Centre for Policy Alternatives report here: https://www.policyalternatives.ca/sites/default/files/uploads/publications/Ontario%20Office/2021/05/Investing%20in%20care%20not%20profit%20report.pdf

What follows is a summary and analysis of these two reports.

Analysis

The conclusions of these reports could not be more diametrically opposed.

The London School of Economics (LSE) report strongly recommends deinstitutionalization - seeing institutions as a function of stigma and prejudice, and therefore as a human rights violation. It promotes a well-funded, comprehensive community care system as vital to preserving the quality of life, well-being, autonomy and self-determination of people with disabilities and older adults.

The Centre for Policy Alternatives (CPA) report argues that more money should be invested in institutions to build, rebuild, or renovate, but that they should be non-profit. It urges the Federal government to maintain the institutional status quo, but to fund it as an essential service, and it suggests that the non-profit sector needs the assistance of an independent agency to help non-profits to build capacity in order to appropriately manage their facilities.

The London School of Economics (LSE) report is much more closely aligned with Seniors For Social Action's position that people with disabilities and older adults deserve to remain integrated in their homes and communities, should have the same rights as the rest of the population to exercise choice and control, and that the days of segregating them in institutions in order to serve the needs of companies, service providers, and unions should be over. Institutions do not belong in a 21st Century reform of long term care. By providing more funding to home care as Denmark and some other countries have done, and investing only in small, non-profit residential accommodation rather than institutions, a new and better way of caring for people requiring assistance can be created.

The London School of Economics report is the second from researchers at highly respected and acclaimed universities to suggest that continuing to invest in institutional models of long term care is misguided and unsustainable.

Late last year the Ageing Well report by Queen's professors Drummond, Sinclair, and research assistant Bergen made the same case, arguing that continuing to institutionalize older adults was unsustainable financially. It recommended a much heavier investment in home care.[3]

SSAO considers the London School of Economics and Queen's reports to be more supportive of a more sustainable, modernized system of long term care that is based on the preferences of

[3] The Queens report can be viewed at: https://www.queensu.ca/sps/sites/webpublish.queensu.ca.spswww/files/files/Publications/Ageing%20Well%20Report%20-%20November%202020.pdf

older adults and people with disabilities, rather than those of government, unions, some academics and professionals, and service providers.

THE REPORT BY THE LONDON SCHOOL OF ECONOMICS

Martin Knapp (Lead Author)
Professor of Health and Social Care Policy, Professorial Research Fellow in the Care Policy and Evaluation Centre (CPEC; formerly PSSRU) London School of Economics and Political Science, (LSE) Health Policy Department. Director of the School for Social Care Research, National Institute for Health Research (NIHR), England. Professor of Health Economics and Director of the Centre for the Economics of Mental Health, Institute of Psychiatry, King's College, London. Chair of the Scientific Advisory Board of the Horizon 2020 project PECUNIA, aiming to establish standardised costing and outcome assessment measures for optimised national health care provision in the European Union. Advisor to government departments and other bodies in the UK and elsewhere, and to international bodies such as the European Commission and World Health Organization. Member of the World Dementia Council.[4]

<u>Introductory Statement – Report by London School of Economics</u>

The London School of Economics Report begins with the statement: "This Report is about home. It is as simple –and as powerful – as that. Home is where we form our sense of self –the very stuff of our identity. We do so in close association with others. Home is also the material expression of self – a sort of scaffolding that holds us together. In our homes we see ourselves reflected back –even in the small things like a flower vase or a family picture. It is quintessentially private. And yet home is also public. Our front doors beckon others in. Outside, we engage with the community – neighbours, shopkeepers, bus drivers. They are part of who we are. Living life my way and in the community is the very essence of independent living. And

[4] Other authors include **Eva Cyhlarova** London School of Economics and Political Science, Personal Social Services Research Unit. PhD Oxford; **Adelina Comas-Herrera** Co-lead of the Strengthening Responses to Dementia in Developing Countries (STRiDE) project. Project manager of the Modelling Dementia (MODEM) research project, which aimed to estimate the impact, in terms of costs and quality of life, of making interventions that are known to work for people with dementia and their carers more widely available by 2040. Curator of LTCcovid.org, an initiative linked to International Long-Term Care Policy Network that shares evidence and resources to mitigate the impact of COVID-19 amongst those who use and provide long-term care. B.A. and MSc, Universitat Pompeu Fabra, Spain; **Klara Lorenz-Dant** Formerly with the Organisation for Economic Co-operation and Development project looking at the key policy issues around, and current international practices across the care pathway for people with dementia in OECD countries. PhD. From the London School of Economics.

home is a crucial enabler for this to happen. And home is exactly what is denied to large segments of the population."

It reflects the preferences of older adults and people with disabilities.

The London School of Economics Report includes the following points:

- Institutionalization is an extreme form of segregation that amounts to "unconscionable discrimination" that violates Article 19 of the UN Convention on the rights of persons with disabilities to live independently and be included in the community;
- Systems have rationalized institutionalization as "an appropriate response to human difference, as cost effective, and as an efficient way of delivering care and services. The report argues that it is none of these, and counteracts these "false narratives" that are rooted in the outdated conception of welfare going back to the mid-20th century that produced the "historical accident" that institutions were the way to proceed;
- "Humanity is at an inflection point where deinstitutionalization needs to be taken seriously, inquiry is needed into why institutional options still exist, and how the narrative can be changed and conversations altered to steer away from congregate options toward more community-based solutions;
- The 21st century "points in a radically different direction" and the report hopes to "give courage to those who seek change" as part of a "deeper conversation" on "the need for, and the possibilities of, a new and wider policy imagination for all our citizens";
- Those having to live in institutions are denied autonomy and choice, provided with poor quality health and social care, they experience social isolation, neglect or abuse and that they are exposed to disproportionate risks of infection, severe illness, and premature death, and how loved ones are also denied their right through restrictive visiting policies, and how it is scandalous that so many people still live in these institutions;
- "Comparisons of community-based services with congregate living for persons with psychosocial or intellectual disabilities have consistently shown better outcomes….in health, quality of life, vocational rehabilitation, self-management, and autonomy" and the report confirms that a majority of people prefer community living rather than institutional or hospital settings;
- A key barrier to deinstitutionalization is "prejudice against persons with disabilities and ageism and therefore a lack of societal commitment to change the status quo." Stigma and a poor understanding of disabilities and discrimination make things worse;
- Allocating a high proportion of public funding to institutionalization ties up that funding, making it less available for community support options.
- An absence of "legal and policy frameworks encompassing new community-based services in many countries creates a 'perverse incentive' in favour of placing persons with disabilities in institutions";

- Barriers to deinstitutionalization include insurance based health systems only reimbursing for congregate care, thereby encouraging providers to keep institutions occupied, as well as institutions being major employers in remote locations;
- Institutions cannot be closed until adequate community services are in place, and that investment in community services needs to be sufficiently generous to change the balance of institutional vs community care, thereby avoiding adverse consequences like homelessness;
- A major barrier is that key decision makers do not listen to the views of the people directly affected by their policies, nor do they respond positively to their preferences and it is this failure to recognize their needs and their rights that leads to insufficient government budget allocations for their preferred services and supports;
- The problem of large donors misallocating funds to institutional care instead of supporting community-based initiatives that promote community living because institutional care is an easier "sell" provides more resources to institutions;
- Deinstitutionalization is necessary to provide older and disabled people with equal rights to live independently and be included in their communities, and good community care may involve a mix of services across a number of different organizations with coordinated access necessary to avoid "silo problems" and gaps in support;
- Deinstitutionalization may also involve the need for "double-running costs" in the short term as resources are shifted from institutions to the community. Budgetary savings are more likely to be secure once large institutions have closed. However this may represent a barrier to policy change in the interim;
- Long term timelines and financial commitments to deinstitutionalize do not offer easy political benefits since closing institutions and making the shift to community-based services only becomes obvious years after they are initiated - often beyond electoral cycles.
- Successful deinstitutionalization requires long term service planning, financial commitment and policy that "looks beyond the electoral cycle", so it requires a commitment to offer a better quality of life to stigmatized people currently subjected to mass institutionalization.

The Report's Recommendations

1. Improve societal awareness and tackle discrimination by addressing prejudice against persons with disabilities and ageism, including stigma and discrimination through legislative and other channels.
2. Involve persons with disabilities and older person in all discussions of policy change and practice development.
3. Establish community-based care to reduce the likelihood of institutionalization, promote informed decision making, choice, and control over decisions affecting individuals' lives,

inclusion in the community, and to ensure appropriate supports are in place to prevent adverse effects of deinstitutionalization initiatives. As part of this ensure that institutional culture is not replicated in community-based settings and that human rights are preserved. Provide assistance to families where needed.

4. Commit adequate funding to community based-support to ensure a high quality community system of care over the long term by transferring resources from institutions to the community, and plan for double running costs in the short-term until all resources tied up in institutions can be released.
5. Improve legal and policy frameworks to ensure the community-based supports are incentivised and institutionalization is discouraged.
6. Respond to pandemics and other emergencies by committing adequate resources to health and care systems to protect persons with disabilities and older adults including ensuring staff training in infection control and prevention, provision of PPE, and other resources. Recognize that infection prevention and control are more difficult in larger, more crowded facilities, and ensure that residents and families participate in decisions where freedoms may be restricted.
7. Commit to long-term action, financial commitment, service planning and monitoring to ensure successful deinstitutionalization and a better quality of life for persons with disabilities and older adults.

REPORT BY THE CENTRE FOR POLICY ALTERNATIVES

Pat Armstrong (Lead Author)

Former Canada Health Services Research Foundation/Canadian Institute of Health Research Chair in Health Services. Co-Director of the Ontario Training Centre, research Professor, Board of Institute of Health Research, and former Chair, Sociology Department at York University. Director of School of Canadian Studies at Carelton. Fellow of the Royal Society of Canada. On Board of the Canadian Health Coalition and the Canadian Centre for Policy Alternatives. PhD in Sociology, Carelton. M.A. Canadian Studies, Carleton. B.A. in Sociology, University of Toronto.[5]

[5] Other authors include: **Hugh Armstrong** Professor (Retired) Social Work, Political Economy, Sociology, Carleton University 1999-2013. - Director, Access and Assessment, Centennial College, 1991-93; Associate Dean, School of Communications and General Studies, Centennial College, 1987-91. Research Associate, Ontario Council of Regents for the Colleges of Applied Arts and Technology (on secondment), 1991. B.A. History and Political Science; M.A. Sociology, Carleton; PhD., Sociology, University of Montreal. **Dan Buchanan** Policy consultant, health and social policy. Formerly with Ontario Treasury Board Secretariat and Premier's Council on Health Strategy. Former Director of Policy with AdvantAge Ontario. Hons. B.A., Public Administration, University of Manitoba. Masters of Public Administration and Policy, Queen's University. **Tony Dean** Senator representing Ontario. Former Cabinet Secretary and Head of Ontario Public Service 2002-2008. Former Professor, Public Policy, Graduate School of Public

Introductory Statement – Report by Centre for Policy Alternatives

The Centre for Policy Alternatives report begins with the statement "The evidence is clear, overwhelming and tragic: Canada has a fundamental problem providing quality long-term residential care (LTC) to those whose lives and well-being depend upon it. Although many LTC homes did not experience high COVID-19 death rates, over two-thirds of Canada's overall deaths occurred in these homes, a ratio more than 50% higher than in other OECD countries. This catastrophe is rooted in decades of underfunding and neglect, as the recent reports by Ontario's Auditor General and Ontario's Long-Term Care COVID-19 Commission (the Commission) have laid bare. Addressing these problems will require comprehensive reform: increased government funding, reduced wait lists, better standards of care and staffing, effective enforcement, and far less contracting out. Crucial to success, as the Commission rightly acknowledges, will be limiting the profit motive in delivering this essential service."

This report is about attempting to fix institutions, not creating real homes for older adults and people with disabilities.

The Centre for Policy Alternatives report makes the following points:

- Long term residential care was never included in the Canada Health Act, so it was never required to be included in health care insurance plans delivered by provinces.
- This meant that Federal funding would not be made available under the Act to support the long term care system. The report argues that LTC facilities are as essential as hospitals, therefore should be funded accordingly.

Policy and Governance, U. of T. Joined Ontario Public Service in 1989 after 10 years in public sector collective bargaining. B.A. Sociology and Social Anthropology, University of Hull. M.A. Sociology, McMaster. **Arthur Donner** Economic consultant. Hons. B.A. and M.A. in economics and finance from the University of Manitoba, PhD from the University of Pennsylvania. **Gail Donner**
Retired professor and former dean of Lawrence S. Bloomberg Faculty of Nursing, University of Toronto. Director, Nursing Education and Research, Hospital for Sick Children. Executive Director of the Registered Nurses Association of Ontario. Chair of Nursing at Ryerson. External advisor on Home and Community Care to Ontario Minister of Health and Long Term Care 2015-2018. **Alex Himelfarb**
Former Clerk of the Privy Council (Canada), Secretary to Cabinet in three administrations. Director of Glendon School of Public and International Affairs, York University. Chair of Steering Committee of the Canadian Centre for Policy Alternatives. Advisory Committee to the Auditor General. **Sharon Shotzberg-Gray** Lawyer and former President and CEO of the Canadian Healthcare Association – federation of provincial and territorial hospital and health organizations. **Steven Shrybman** Partner at Goldblatt Parners LLP, who has worked closely with Health Coalitions and trade unions.

- This and the need provincial governments having embraced austerity has led to various forms of public-private partnerships founded on the belief that investment capital would be available from private sources not otherwise available to government. The report argues that this is fiction and only leads to longer term costs and risks.
- Dependence on private investors is described as "self-imposed constraint by government" which ends up committed to paying for LTC facilities irrespective of how they are "financed, owned, or operated".
- Governments at provincial and federal levels should be funding capital costs as they do for public hospitals especially since the cost of borrowing is higher for the private sector .5% to 2%.
- Two decades ago the Ontario government began subsidizing the sector's capital costs thereby setting off an expansion of the private sector which now owns 58% of LTC beds and managing others contracted out by non-profits.
- Competition is intended to improve services, but there is no competitive market in LTC because of long waiting lists, and care should be mission driven according to the COVID-19 Long Term Care Commission.
- Quality is less in for-profit facilities, especially those that are chain operated.
- For-profit providers are not more efficient. Efficiencies can only be found by cutting staffing which diminishes care.
- Operational funding for LTC is "barely adequate to meet resident needs at a basic level (no reference is given to support this statement).
- Government provides both capital and operating funding to LTCs according to a sliding scale that reflects differential costs of building, whether in large cities, smaller or rural settings.
- Assets from this funding remain with the LTC operator, who may find other uses for the assets and real estate.
- Any unused portion of the Construction Funding Subsidy (CFS) can also be taken as profit.
- Funding is approximately $66,000 per resident per year with 70% of the funding used for nursing, personal care, food, and support services. The other 30% is allocated for cleaning and sanitary supplies, but profit can be taken if these supplies are unneeded.
- Investor returns are sought from these grants and subsidies and some companies also provide management services to others.
- Resident co-payments for accommodation are another source of profit, as is the real estate facilities sit on, and companies may also contract out services such as food, laundry, housekeeping etc.
- Non-profit facilities typically spend every penny of public funding on resident care and many supplement the provincial subsidies via charitable donations or municipal tax revenues (no reference is given in support of this statement).

- The industry argues that it is too big to fail because of the dominance of for-profit providers in the system which allows it to exert influence on government policy to fund and regulate in ways that are acceptable to investors.
- Enterprise risk is shifted to its private partner but in fact government cannot simply abandon residents of failed facilities, and has moved to shield the industry from specific negligence claims by residents and families.
- In spite of the Act stating that Ontario is committed to the promotion of the delivery of long term care home services by not for profit organizations, the capital funding regime does the opposite in order to attract equity investors, thereby posing a problem for non-profits that have little access to equity capital because they lack the capital reserves needed to qualify for a mortgage through various channels.
- The Federal government has committed $3 billion over five years focused on accreditation standards and safety improvements such as improved ventilation systems.
- Accreditation standards will not be a panacea nor will enforcement standards recommended by the Commission if LTC providers finesse or circumvent them to avoid additional costs.
- The allocated 30,000 beds promised by government and present capital funding should go to non-profit providers – hospitals, municipalities, and other non-profits in its entirety.
- Federal and provincial infrastructure funding and mortgage programs should be available to non-profits with or without capital reserves.
- A new public agency should be established to assist non-profits to plan, finance, and operate LTC facilities according to best practices.
- A task force should be mandated to plan phasing out of for-profits by transitioning beds that do not meet design standards with licenses that will expire in 2025 to non-profits.
- AdvantAge has called for a separate program stream for non-profits and for government to remove barriers to provincial and federal infrastructure and mortgage programs to facilitate capital development and redevelopment.
- A provincial agency (to replicate the benefits of chain ownership) is needed to assist non-profits that lack the necessary financial and management infrastructure to cope with the “demands of building and operating a modern LTC home” and failing to address this could cause non-profits to “languish”.
- C bed licenses (operating under standards established 50 years ago) will expire in 2025 and need to be rebuilt. B beds that do not meet 1998 standards will also expire in 2025 and also need to be rebuilt – rebuilds are currently underway.
- A strategy is needed to meet the care needs of those served by these for-profits and reduce wait lists in their communities with Ontario signalling its willingness to fund the rebuilding of most for-profits. The report recommends that the government establish

"an independent task force to develop a plan for licensing new and redevelopment homes to the non-profit sector".

- LTC institutions are "homes" and places "where people can live out their lives with dignity".

The Report's Recommendations

1. The province commit to proceeding with an orderly and phased reduction of for-profit LTC, whether in homes owned or operated by such companies.

2. New licenses for 30,000 LTC beds, which the province has committed to, be allocated entirely to the non-profit sector - municipalities, hospitals, other public entities, and not-for-profit providers.

3. Both levels of government remove the impediments that now limit or prevent not-for-profit and municipal LTC providers from accessing the funding required to build or rebuild LTC homes.

4. The province create an independent agency, with a mandate and resources to provide non-profit homes with the capacity they need to efficiently manage the financial and operational demands of providing high quality LTC.

5. The province establish an independent task force to take up the Commission's recommendation that it: "...urgently implement a streamlined expedited approval process for creating redeveloped and new long-term care beds that accommodates the participation of existing and new not-for-profit and municipal licenses..."

6. The federal government pass LTC legislation that recognizes that LTC is necessary health care and commits to ongoing funding for these essential services.

Conclusion

The London School of Economics and Queen's University reports reinforce SSAO's position calling for an end to institutionalization on both moral and financial grounds.

The Centre for Policy Alternatives report favors the continuation of institutions as long as they are non-profit, receive support to deliver institutional services, and are well-funded by government. This report does not support SSAO's position that Ontario needs to end its reliance on institutions and listen to older adults and people with disabilities when they say they do not wish to be institutionalized.