Care Homes in a Turbulent Era
IN A TURBULENT ERA SERIES

These are turbulent and changing times. The longer-term effects of phenomena such as Covid-19, climate change, the rise of China and Brexit as well as populist politics on businesses, the economy and geo-politics are still unknown. Given these rapidly changing economic and social norms, businesses, organisations and institutions must be nimble to thrive. Focusing on one area at a time, this series seeks to investigate best practice, cutting-edge research and new ways of operating in this turbulent era.

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Care Homes in a Turbulent Era
Do They Have a Future?
Edited by Pat Armstrong and Susan Braedley
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Contents

List of contributors vii
Acknowledgements x

1 Care homes in crisis: promising ways forward  
   Pat Armstrong and Susan Braedley 1

2 Piercing the corporate veil: nursing home ownership in  
   turbulent times  
   Hugh Armstrong 19

3 What’s critical to care?  
   Pat Armstrong, Jacqueline Choiniere, Charlene Harrington, and Marta Szebehely 34

4 The crisis in the nursing home labour force: where is the  
   political will?  
   Pat Armstrong, Frode F. Jacobsen, Monique Lanoix, and Marta Szebehely 50

5 Negotiating internal and external boundaries of nursing homes during Covid-19: a case study from Norway  
   Gudmund Ågotnes and Frode F. Jacobsen 67

6 Are safer, welcoming care homes possible? Considering physical environments  
   Susan Braedley and Pat Armstrong 82

7 Family members and nursing home care: lessons from Ontario and Sweden during Covid-19  
   Ruth Lowndes, Jacqueline Choiniere, and Petra Ulmanen 99

8 Equity and diversity in nursing home care: lessons from Canada and Sweden  
   Prince Owusu, Susan Braedley, and Palle Storm 117
9 Regulation and accountability in the care home sector: expert commentaries
   Albert Banerjee, Hugh Armstrong, Pat Armstrong, Frode F. Jacobsen, Charlene Harrington, and James Struthers

10 Making joy possible in care home policies and practices
   Susan Braedley, Pat Armstrong, and Janna Klostermann

Index

137

151

169
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1. Care homes in crisis: promising ways forward

Pat Armstrong and Susan Braedley

Covid caused tumult everywhere. It exposed and exaggerated weaknesses in systems, challenging assumptions, policies, and practices. It also exposed and exacerbated inequalities, including those related to gender, age, class, race, and immigration status (Ahmed et al., 2020). This was certainly the case in those places – called nursing homes, long-term care homes, care homes, among other names – that provide for older people with significant care needs. Throughout high-income countries, especially before vaccines, Covid hit nursing home residents hard (Akhtar-Danesh et al., 2022; Comas-Herrera et al., 2021). As death rates soared, nursing homes received considerable public attention. Responding to the outcry, governments intervened with multiple strategies, providing supplies, new regulations, new labour force approaches, and new money. Commissions were set up to investigate what went wrong and to recommend what should be done.

But this is nothing new. According to a study conducted early in the pandemic, over 100 investigations into problems with care homes had been carried out in Canada alone since 2000 (Estabrooks et al., 2020). And Canada is not the only country generating reports and recommendations on long-term care, as any Google search makes clear. Research by our team on nursing home scandals in five countries shows that all these scandals resulted in government action, but none of these actions addressed underlying structural issues or led to fundamental change (Lloyd et al., 2014). Whether or not there will be fundamental positive change in the wake of the pandemic or a return to business as usual – or even worse conditions – is an open question.

At this critical juncture, we contribute to the urgent demand for this fundamental change through an analysis based on years of international research. For over 15 years, members of our team have been studying and comparing long-term care in Canada, Germany, Norway, Sweden, the United Kingdom, and the United States, looking for promising policy and practices that produce conditions that promote dignity and respect for all those who live in, work in, and visit care homes. We speak of promising practices and of ideas worth sharing because we think context matters, which limits the usefulness of many
universal formulas for change. The evidence we have gathered demonstrates the continuing need for care homes to be central to social welfare regimes, and the necessity to move them from providing primarily custodial services to offering care that addresses inequities and builds community. But our comparative research has revealed problems as well as promising practices in the ways care homes are conceptualized, organized, funded, regulated, and staffed in many jurisdictions.

Our research is framed by feminist political economy, a theoretical and methodological approach that attends to intersectional inequities and both production and social reproduction through attention to political, economic, and social relations as they change, along with ideas, over time (Armstrong & Armstrong, 1990; Armstrong & Connelly, 1999; Estes, 2001; Braedley & Luxton, 2010). We understand politics and economics, discourses, and ideas as integrally related, and operating at multiple levels. Like Estes (2001), for us care “can be understood only in the context of social conditions and issues of the larger social order” (p. 1). This approach means that in our research on care homes, we pay attention to the conditions of work, assuming that the conditions of work are the conditions of care. We assume that care is a relationship, albeit one characterized by inequities of power, and that gender, racialization, class, and sexuality all matter – and matter at all levels of analysis.

In writing this book, our team draws on a major ten-year project and a host of other research projects, including several three-year international and national comparative studies, and other smaller projects. In these projects, our international, interdisciplinary team has used multiple methods to organize our investigations around four major themes: approaches to care, financing and ownership, work organization, and accountability structures. While we have used traditional research methods to explore areas such as staffing levels and labour force strategies, government regulations and privatization, we have also used what we call rapid, site-switching ethnography to study homes that are publicly funded and regulated and that provide 24-hour nursing care (Armstrong & Lowndes, 2018). In our major project, this method involved taking teams of researchers into a care home over the course of a week. After conducting significant background research on each home, its local community, and the jurisdiction in which it was located, we worked in shifts and in teams to observe and interview from 7 a.m. until after midnight. We continually reflected together on what we found, and shared both our data and our analysis, bringing what we called fresh eyes to the research by ensuring teams were both international and interdisciplinary. We continue to use scaled-down versions of these methods in our ongoing research.

Our research includes all those who live in, work in, visit, and manage care homes, because we assume that all these people are experts on the home, and because we want to capture the complexity of the community. We attend to
Care homes in crisis

noises and silences, time of day and time for tasks, physical structures, and social relations in our search for policies and practices that treat everyone involved with dignity and respect, and that support them in reaching their potential. Because we assume contexts matter and at multiple levels, we search for promising practices rather than single, universal best practices. At the same time, we record problematic and unpromising practices. We work to identify tensions and contradictions emerging from policy and practices that might succeed in advancing dignity and respect in one way while undermining it in another. In our view, it is these points of tension that offer a basis for change.

The research in this book has been, and continues to be, a collective effort. All the authors have helped to collect and analyze the huge data sets that inform these chapters. We continually engage with each other’s perspectives, spurring lively arguments that have led to new research questions. Although each chapter has specific authors named, all of the chapters, as well as the book itself, reflect these collective efforts.

In this chapter we set out the overall context for nursing home policy and practice in the jurisdictions we study – Canada, Germany Norway, Sweden, the United Kingdom, and the United States – before and since Covid emerged, beginning with the concerns for aging populations and government responses.

BEFORE THE PANDEMIC: THE CARE HOME CONTEXT

Worldwide the proportion of the population over age 65 has been growing rapidly, as have concerns about “the challenges for health and social systems” (World Health Organization, 2021). Yet warnings about the looming impact of population aging are far from new (Tepe & Vanhuysse, 2009). In the mid-twentieth century, a Canadian government spokesperson claimed that the “astounding increase in the number of persons living beyond 65 years of age is the greatest social problem of our day” (quoted in Struthers, 1997, p. 176). But strategies to address this “social problem” remain open to debate.

In the post-World War Two period, the welfare state was growing in high-income countries and collective government responses were generally expected and accepted. In Canada, the deplorable conditions in private nursing homes prompted the government of the day to respond to this “greatest social problem” by providing more funding, more regulation, and some public care homes. However, the extent and nature of these responses, as well as the dominant ideas on which they were based, varied across jurisdictions. Comparisons are complex and difficult to capture in a short space, but some overall patterns are clear. Esping-Andersen’s (1990) division of countries into three forms of the welfare state has been widely criticized, especially for failing to take gender into account and for limiting his perspective to a few countries (e.g., Bambra,
2007; Sainsbury, 1994). But his three criteria used to determine these forms remain useful in understanding differences among the countries involved in our research. They are: the extent to which an individual’s welfare relies on the market (including pensions, health insurance and unemployment); the extent to which state programs reduce inequality; and the extent to which the state relies on families, the voluntary sector, and the market for welfare provision.

While all these countries expanded welfare programs in the mid-twentieth century to extend some care to the older population, Norway and Sweden went the farthest in assuming collective responsibility for elder care and in ensuring care was equitably provided through non-market means, followed by Germany, then Canada, and the United Kingdom (Harrington et al., 2020a; Szebehely & Meagher, 2018). The United States approached care in the least collective and the fewest non-market ways. Most of these countries expanded access to hospital care. Even the United States did so with Medicare. But Norway, followed by Sweden, moved farther in providing long-term care at home and in residential facilities.

The romance with welfare states’ expansion came under increasing attack beginning in the early 1970s. Justified by a recession and in the name of austerity, neoliberal strategists promoted markets as the basis for service provision, arguing that the state should not be involved in the production and ownership of goods and services, while applying New Public Management approaches to instill market logics into any public services that remained (Hermann, 2021; Mudge, 2008). Neoliberal strategies have multiple components and variations but are based on a faith in markets as effective and efficient. Neoliberal approaches to regulation are primarily about supporting markets. Inequalities are perceived as regrettable but inevitable, and best addressed by stimulating wider market participation (Braedley & Luxton, 2010). Here too, the growth in the older population played a role. Even though a majority of those over age 65 in high-income countries live healthy and independent lives (McGrail, 2012), there were declarations that an aging “tsunami” would bankrupt health care and necessitate cutbacks in public services.

The promotion of neoliberal strategies to provide efficiency and choice was combined with calls for “aging in place,” which shifted responsibility to families and individuals. At the same time, a growing movement against institutional care gathered momentum, especially for children, those who were intellectually disabled, and the mentally ill (Struthers, 1997). But while there were calls for alternative care in the community, too often the community care was not there. Instead, North American governments especially used the critiques as a way to save money by closing institutions. Companies entered the void left by the closures, as a way to make profit (Estes & Harrington, 1981). Competitive bidding for some public services and cutbacks in others, public-private partnerships, and outsourcing all became common. There was
an increasing reliance on imported female labour and on both their part-time and casual employment (Brennan et al., 2012). And all these public service constraints, cutbacks, and failures to meet demand meant more unpaid work in households and communities, predominantly work done by women.

Care homes were affected by all these shifts. There was de-regulation in areas such as ownership and re-regulation of others, such as resident meal-times. Accountability was increasingly defined by metrics counting what could be counted and doing so in ways that made the primarily female and increasingly racialized and immigrant labour force in elder care responsible for the quality of care. At the same time, these forms of accountability helped undermine participation in decision-making and broader democratic responsibility (Power, 1999).

The shift to care home market strategies was particularly evident in North America and the UK. In Ontario, Canada’s largest and most populated province, for example, competitive bidding for publicly funded nursing homes had awarded nearly 60 percent of the homes to for-profit firms by 2022, and services within the remaining public and non-profit homes were increasingly outsourced. Meanwhile only half of the overwhelmingly female staff was employed full time and 40 percent were racialized (Armstrong, Armstrong, & Bourgeault, 2020; Gillese, 2020, p. 5). This staff was increasingly required to document their work activities on new technology systems, taking time away from care. Most of the funding still came from the public sector, with resident fees regulated and accompanied by subsidies to prevent income from being a barrier to entry. However, the limited number of spaces available provided a barrier, with room for less than 4 percent of those over age 65. In and out of the nursing home, families were expected and required to provide more of the care.

Sweden and Norway remain committed to collective responsibility for care, but they have not escaped these neoliberal and New Public Management strategies. Sweden more than Norway saw an increase in for-profit service provision of publicly funded care, along with an increase in family care and out-of-pocket payments (Ågotnes et al., 2020; Szebehely & Meagher, 2018). Outsourcing has increased in these Nordic countries and the available spaces in care homes has not kept up with demand. More staff are employed on a part-time or casual basis, and the reliance on migrant labour has grown (Storm & Lowndes, 2019). However, the Campaign for the Welfare State in Norway (Herning, 2015) managed to halt and to some extent reverse the development of for-profit ownership. Overall, neoliberalism’s impact is less evident in these Nordic countries.

Beginning in the 1980s, there were also movements to transform the care within homes rather than simply call for closure of the homes (Chapter 6). In the US, the cultural change movement promoted “person-centred” care
(Koren, 2010) that would transform institutions into homes. This movement criticized nursing homes as impersonal, rigid institutions that undermined residents’ dignity and respect, and called for models that would provide more flexibility for residents and staff, while rejecting large facilities. The movement has had a limited impact to date. Some cultural change models, like the Eden Alternative, have established so many rules that this alternative has become institutionalized. In our study of care home models (Armstrong et al., 2019) we found that the principle of person-centred care was widely accepted by staff, residents, and families, but the structural conditions allowing such an approach were limited.

While the structural conditions varied across countries and even within them, there are common patterns. Women are the overwhelming majority of residents and staff in all countries, reflecting and perpetuating inequities (Armstrong, 2009; Braedley, 2013). Women tend to live longer than men, but with complex health issues that require care. They are also more likely than men to be poor in old age and less likely than men to have someone to provide unpaid care at home. These circumstances leave women more dependent on nursing homes. Women’s limited options in the labour force, combined with assumptions about the unskilled nature of care work and women’s “natural” capacities for care work, contribute to their dominance as care workers in these low-paid, often precarious jobs (Chapter 4). Although care home unionization rates are relatively high in most countries included here, neoliberal policies worked to suppress and reduce the price of labour through multiple strategies, including de-regulation, contracting out, and increasing the quantity and intensity of job tasks (Armstrong & Baines, 2021). Care home labour shortages have increasingly been addressed through international migration, providing women workers mostly from the Global South (Lightman, 2019). The result has been an increasingly racialized, immigrant, precarious, and under-valued labour force with long-standing high turnover as these workers exit to jobs with better working conditions.

Another common pattern is that the supply of spaces in nursing homes has not kept up with demand, even in Norway and Sweden, where investments in care homes have been greater than in other countries. As a result, the complexity of resident care needs has steadily increased while staffing has stayed the same or dropped in terms of the numbers or education needed. Although in all six countries most residents have some form of dementia, that their other care needs can be more easily addressed through clinical interventions encourages a focus on medical rather than social approaches to care.

There are, however, some important differences. For-profit ownership has grown in all the countries, but by far the least in Norway, followed by Sweden. Reflecting a lingering commitment to universalism, this helps explain why Norway and Sweden still have much higher staffing levels than the other
countries. And unlike the other countries in our research, Norway and Sweden have not turned to detailed documentation of resident care or accountability for staff work (Chapter 10). Staff have more autonomy, they work more in teams, and they have a more flexible division of labour than in the other countries we studied. These long-standing practices are similar to the kinds of approaches promoted by the cultural change models.

These were the major conditions of nursing home care when Covid began spreading at an alarming rate.

SINCE THE PANDEMIC ONSET: COVID LESSONS

The widespread initial policy response to the World Health Organization’s (WHO’s) announcement of the pandemic was to focus on hospitals. Personal protective equipment (PPE), along with other resources, were concentrated there, and hospitals were encouraged to send patients home or to long-term care to make room for Covid patients. When it became obvious that many care homes were being battered by Covid, the primary strategy was to prohibit movement in and out of care homes by locking out visitors and restricting paid workers to one workplace. Homes also reconfigured furniture and spaces, provided more virtual care services within the home, tested staff, residents, and visitors, and used more PPE and hand-washing (Clarke, 2021). Governments intervened to varying degrees, introducing new regulations on, for example, scope of practices and the hiring of immigrants, as well as offering extra money for wages and for supplements like transportation, training, and childcare. Various commissions of enquiry were set up to investigate what went wrong and why. The Swedish Corona Commission (2020) offered a succinct overview of the issues:

The Commission’s overarching assessment can be simply summed up as follows: apart from the general spread of the virus in society, the factor that has had the greatest impact on the number of cases of illness and deaths from Covid-19 in Swedish residential care is structural shortcomings that have been well-known for a long time. (p. 2)

Our team, along with other researchers, have been naming those structural shortcomings for decades, while also identifying a number of promising practices for moving forward. Our overall assessment, before as well as during the pandemic, leads to at least eight major lessons for the transformation of care homes.
COVID’S LESSONS

1. We Need Coordinated, Committed Government Leadership

When Covid hit care homes hard, governments were called on to ensure vaccines, protective equipment, and a care labour force, and they stepped up to intervene. The new strategies challenged the decades of neoliberal emphasis on markets, individual choice, and responsibility, as well as on small government, especially in relation to services and labour. There was widespread support for government investment, along with the coordination and regulation of services to control the virus.

At the same time, governments were criticized for failing to adequately protect the older population. It became clear that collective action is required to do so and that this means government funding, regulation, and enforcement. Government leadership need not mean a one-size-fits-all approach but can be based on a set of shared standards to be met in a variety of ways, allowing adaptation to particular populations and locations, while ensuring equity in access and quality.

2. We Need to Remove Profit from Care

At the same time as the need for government leadership became clearer with Covid, the problems with for-profit care also became more obvious. Neoliberalism promoted for-profit services and their methods as more efficient and cost-effective, with competition ensuring quality of care. Just-enough care, at the lowest possible cost, provided by those with just-enough training became the goal. Throughout the high-income countries, neoliberalism led to considerable “privatization of profits and the collectivization of costs” (Hermann, 2021, p. xiv), although there has been considerable variation in the extent of this approach.

Canadian research during Covid revealed the significantly higher death rates in for-profit homes (Stall et al., 2020), along with continuing significant profits (Oved et al., 2020). The for-profit homes owned by chains were particularly dangerous for residents (Stall et al., 2020). Research completed before the pandemic already showed a pattern of poorer quality in for-profit homes, as indicated by such measures as lower staffing levels, more verified complaints, and more transfers to hospitals (McGregor et al., 2006; Ronald et al., 2016; Ronald et al., 2008; Tanuseputro et al., 2015). Given that publicly funded nursing homes as a group are overwhelmingly more popular and run much longer resident waitlists, for-profit homes cannot be justified on the basis of
the argument that competition for customers improves quality and efficiency. There is, then, little justification for putting public money into profits.

Nor is there much justification for outsourcing services within care homes (Armstrong & Armstrong, 2021). Agency staff are not cheaper, and they disrupt continuity in care. Typically used as temporary fill-ins, they do not know the residents or the staff. They create more work for permanent staff who must orient and train them, and more discomfort for residents who do not know them. Contracted food and laundry services cannot readily respond to individual resident needs, and they charge extra when they do. Because those working for outsourced services must respond to different employers, any attempts at teamwork among staff are undermined. Outsourcing management services brings even more for-profit strategies into the care home while making managers accountable to an external corporation rather than to the community in and outside the home.

3. **We Need to Improve Working Conditions in Long-term Care, which in Turn Will Improve Living Conditions**

Our research team has long argued that the conditions of work are the conditions of care and that in considering those conditions we have to think about both the paid and unpaid work carried out by all those who live, work, and visit in long-term care (Armstrong, 2023). Focusing on residents, as so much reform has called for, means first creating the conditions that make such a focus possible.

A critical condition is an appropriate staffing level. A host of research demonstrates that adequate staffing is a necessary prerequisite for delivering quality care (Harrington et al., 2016). Long before Covid, our research showed that without enough staff, even the most critical tasks often remain undone and there is little, if any, time to respond to individual resident needs (Armstrong et al., 2009). Recent US research demonstrates a clear link between staffing levels and Covid-19 outbreaks, providing just one example of how critical the level of staffing is to care (Harrington et al., 2020b). Low staffing levels are not only a risk for residents; they are also a risk for staff, as they rush to complete tasks, and as frustrated residents lash out in response to inadequate care. As increasing numbers of residents have complex care needs, it is more important than ever to base minimum staffing level requirements on an assessment of resident needs.

Numbers are not enough to create conditions that allow staff to deliver responsive care based on their skills. Staff need appropriate pay and benefits, including sick leave, based on recognizing the skilled and demanding nature of their labour. They need the time, the flexibility in the division of labour, and the autonomy to tailor their responses to specific situations and individuals.
They also need the support of teams and of the care home leadership. This, in turn, means that staff are employees of the home, employed full time or permanent part time to allow for continuity in care and for staff to support each other. It means as well that less time is spent on recording what they do and more time consulting together on how best to address issues as they arise.

We also need to recognize the unpaid work done by families, residents, and volunteers and to assess how their conditions can be improved. More staff, with more autonomy and more flexibility, are critical conditions for this unpaid labour. Without sufficient staff, families and volunteers are pressured to take on significant aspects of the care work (Streeter, 2023), while residents may be prevented from doing the work of self-care and from assisting others because it takes other people’s efforts to support residents in doing this work (Braedley, 2023). Recognizing that this labour by residents, families, and volunteers is work allows us to uncover the conditions that support it, when such contributions are appropriate. Exploring the conditions that support residents, to the extent of their capacities, to provide care for themselves and assistance to others enriches the workplace. Residents, like families and volunteers, can for instance, provide a critical monitoring function, alerting staff to resident needs – but only if leaders and staff promote such monitoring. When families and volunteers were locked out during Covid, their essential contributions became more visible. The Covid experience provides the opportunity to identify the conditions that support these contributions.

4. We Need Training for Staff, Families, Residents, and Volunteers, Including in Infection Control

Care is skilled work, and the skill requirements are continually changing with new health threats, new techniques, and new demands related to the increasingly complex needs of residents. Long before Covid, research demonstrated the need for a higher proportion of Registered Nurses on staff (Centers for Medicare and Medicaid Services, 2001) and more formal training for all staff, especially for those who provide the bulk of the direct care. The various commissions set up during Covid have recognized the need not only for more training, but for more regular training in areas including infection control, dementia, and cultural sensitivity. Covid has also taught us the importance of in-person, hands-on education.

As families and volunteers were first blocked from entry into care homes and then slowly allowed to return, both their contributions to care and the need to instruct them on infection control became obvious. Families became increasingly aware of the need to know about policy changes at all levels, as well as about ways to engage safely with residents and staff. But long before Covid, relatives and volunteers were regularly interacting with a wide range
of residents and staff. Doing so required knowledge of how to interact and not interact, how to communicate, and what policies were in place for everything from responses to fire and violence, to chatting with and assisting residents. Regular education for those doing this unpaid labour would support them as well as those who are doing the paid work.

The need for such education is not limited to those doing the paid and unpaid work in nursing homes. Governing bodies require continuing instruction in how care homes actually operate, in how resident needs are changing, and in policies that influence both the daily conditions in the home and those in the future. Just as paid staff require continuing and in-person formal and informal education, so too do relatives, volunteers, and members of governing bodies.

5. We Need Integration of the Community Inside and Outside the Home

Nursing homes offer the opportunity to create communities, balancing privacy and individual actions with social connections and shared activities. Covid emphasized how loneliness and isolation are unhealthy. It is not only families and staff who can provide meaningful relationships, however. Constructing ways to bring residents with similar capacities and shared interests together can support the creation of communities within the care home. Similarly, innovative social spaces within the nursing home can attract and bring in people from outside, expanding social connections and making the home more lively and diverse.

At the same time, communities outside the nursing home can offer opportunities for social interaction and alternative activities. They can provide ways to participate or at least see life beyond the walls. Indeed, connections with the community make the walls more transparent and permeable.

6. We Need Physical Environments that Reflect and Respond to Communities Within and Outside the Home

The physical design and the location of a care home shape the possibilities for living and for work. Homes need to be located where they are easily accessible to staff, families, and the community outside them, while also making the community accessible to residents. Accessibility within the home is equally important, not just in terms of structures that recognize physical, mental, and cultural diversity but in terms of allowing easy movement among various parts of the home.

Covid has taught us the importance of constructing care homes to allow for the temporary separation of homes, areas, and even individuals when infections and other threats strike. Covid has also highlighted the importance
of having private rooms with their own bathrooms, and flexible spaces that allow responses to new issues as they arise. Making such allowances means thinking through how care home construction can help prevent social isolation and ensure care while providing appropriate protection.

7. We Need More Democratic Decision-making In and Out of the Home

Covid made it obvious that nursing homes must be made accountable for quality care and quality work environments. For years, governments to various degrees have been introducing means for measuring, documenting, and reporting on everything from staffing levels to residents’ assessed needs. To varying degrees they have introduced detailed requirements for everything from eating times to room sizes, followed up with inspections. But the evidence supporting these measures and rules is frequently questionable and the enormous documentation requirements take time away from care without significantly improving that care. Inspections are more often about policing than about finding ways to support the enhancement of care. Quality indicators often count what can easily be counted and not what counts for quality care.

We do need regulations, accurate recording, and public reporting on essential data, especially in areas such as staffing levels, injury rates, and hospital transfers, and to ensure that standards are met. However, we also need to assess to what extent these means of accountability support care as a relationship that makes life worth living and care work worth doing.

Such data should be available in accessible form to provide the basis for decision-making at multiple levels. Participation of staff, residents, families, managers, and volunteers in the development, evaluation, and use of the data would significantly improve the data’s effectiveness. Those who live in, work in, visit, and manage care homes are experts on conditions and needs. Establishing meaningful ways that go well beyond surveys to participate regularly in evaluation and in decision-making would make a critical contribution to ensuring quality. Unions are an important means for staff participation but other organized means for participating are also critical.

It is equally important to create means to participate in decision-making that go beyond elections, both for the communities in which the home is located and for the broader public. This can involve a wide range of mechanisms, from boards and governance committees in non-profit and municipal homes, to community consultation groups, volunteer groups, and more. Regular, accurate reporting on essential components in care is necessary but insufficient to allow for democratic accountability. There is a collective responsibility to monitor care, both to protect this vulnerable population and to ensure public money is well spent.
8. We Need to Attend to the Social, Physical, Medical, and Emotional Needs of all those who Live In, Work In, Visit, and Manage Nursing Homes in Ways that Recognize Diversity

Covid has highlighted that care is not just attending to medical treatment and basic physical needs. Care must support capacities and relationships. Focusing on putting life into years rather than on putting years into lives requires an approach based on recognizing the complexity of care. Covid has made it clear that the social, emotional, physical, mental, and medical health of those who provide care is equally important. Designing long-term care with residents in mind means beginning with this understanding of both care and the community involved in providing care.

This means recognizing that residents, staff, and family populations are increasingly diverse in terms of ethnicity, race, immigration status, sexuality, gender identity, age, and disability (Chapter 9). Ensuring safety, access, dignity, and respect for diverse residents, staff, and families adds to the complexities of care while also providing the basis for rich community interaction. There is no single, best model for care homes but there are countless promising practices that can be used to make care fit communities.

The pandemic put a spotlight on nursing home care, at least briefly. The spotlight offers an opportunity to create care homes constructed around supporting care as a relationship and making life worth living and work worth doing. However, instead of focusing on reforms within care homes, there has been a growing chorus calling for their elimination. According to a report for the European Commission (Šiška & Beadle-Brown, 2020), with Covid,

the defining negative aspects of institutionalisation (the congregation of a large number of people in one building and the deprivation of social contacts) are increasingly blatant and only tend to aggravate with exposure to the virus. (p. 3)

The report goes on to argue for care in the community and for small care homes as the alternative. There is a consensus in all the countries we studied that there is a need for more and better homecare, along with other kinds of community living. This does not mean that there is a similar consensus about the elimination of care homes, or that they all should be small, however.

There are multiple reasons for rejecting homecare as one alternative for all (Armstrong & Armstrong, 2021). First, not everyone has a home, and even for those who do, not every home is safe in physical or social terms. Second, private homes may be isolating and lonely. Third, many of those now in nursing homes require 24-hour care and no government can afford to pay for that in private homes for all who need it. Fourth, care is skilled work requiring training and supports. Depending on families (for those who have families)
usually implies depending on women without formal training, many of whom are doing the caregiving to the detriment of their own health.

Focusing on homecare ignores the benefits that can come from congregate care. When we asked the residents’ council in a Canadian nursing home if there was anything better about living in the nursing home than living in their own private home, they were unanimous in saying yes. They gave four reasons. First, they felt safe, giving the example of someone ensuring they got their insulin. Second, they had company. If they were at home, they would be alone all day. Third, they had activities. Even if they watched a lot of TV in the nursing home, that’s all they would do at home. Fourth, someone made sure there was food, clean clothes, and a cleanroom, which would not be the case at home.

Research in Sweden (Szebehely & Meagher, 2018) indicates that a majority would like to go into a nursing home if they required help with more than two aspects of care. This too indicates that nursing homes can provide an option for care, one more desirable than homecare in various instances.

The homes we studied in Sweden were not small, providing another indication that small homes are not the only option for the future. Land prices alone limit the possibilities for many small homes related to the communities in which people have lived, especially in large urban centres. But there are more positive reasons for larger homes. They can offer economies of scale for services and make it possible for the home to employ their own therapists, doctors, and other specialists. They also offer the opportunity for a broader range of activities and a broader range of residents. It is possible to create smaller units within these homes, as we saw in the Nordic countries, getting the advantages of small within large. At the same time, units are sometimes too small, reducing options for interaction and increasing boredom due to the limited opportunities for activities and to meet other residents.

Our research indicates that we need nursing homes now and in the future. It also indicates that there is no single best way to construct and organize care homes. But we do have many lessons learned from Covid, as well as from the years of research, to guide us in moving towards making care as good as it can be for the communities served by nursing homes and for those who work within them. In moving forward, we have to listen to these communities and respond to them. And we need to move fast, before it is too late for those who need decent care and decent work now.
REFERENCES


2. Piercing the corporate veil: nursing home ownership in turbulent times

Hugh Armstrong

There can be no doubt that the pandemic has hit the residents of nursing homes with horrific severity. In Canada, nursing homes “serve seniors and others who do not need to be in hospital but do need access to 24-hour nursing care not generally available in care programs or retirement homes” (CIHI, 2014). Unlike retirement homes and other types of congregate living directed primarily at seniors, nursing homes receive substantial public funding in Canada and in most OECD countries.

Nursing home residents have disproportionately been infected, been hospitalized, and have died as a result of Covid-19. And they have been socially isolated, as visits by family members and friends have been restricted in part or in whole, and as staff shortages have grown because workers too have been infected. Conditions in Canadian nursing homes – sometimes with three or more beds to a room, with underfunding, agism, and the precarious employment of poorly paid workers – have been held responsible.

These conditions are long-standing. They were documented for decades before the pandemic struck.¹ Two changes have, however, intensified this pernicious situation. One is of course the pandemic itself. The second, which is much less immediately visible, is the accelerating shift to for-profit ownership and operation of the homes, and away from non-profit homes, whether charitable or publicly owned. More specifically and alarmingly, nursing homes have increasingly been taken over by private equity finance (PE) and real estate investment trusts (REITs). This chapter documents the challenges involved in determining just who owns and operates for-profit nursing homes; it then suggests ways in which profit can be reduced or eliminated from them, and notably from those that use PE and REIT financial tools.

The combined effect of population aging and the failure to increase nursing home capacity has meant that their residents are becoming older, frailer, and thus more vulnerable. By July 2020, over 360,000 Covid-19 deaths occurred in the 12 leading OECD countries, with over 154,000 (or 42.7 percent) of them among nursing home residents. The death rate was particularly stark for residents in Canada, where during the early stages of the pandemic, 78.4 percent...
of the country’s deaths took place. In the United States, by contrast, about 40 percent of Covid-19 deaths occurred in nursing homes in the pandemic’s first year (Abbasi, 2022), still an excessively high percentage given that they constituted less than 1 percent of the US population. With vaccination priority assigned to residents and staff in early 2021, the nursing home share in Canada dropped appreciably, but remained the highest among the 12 countries (calculated from Sepulveda, Stall, & Sinha, 2020, appendix table 1). As of August 2021, the cumulative nursing home share of all Covid-19 deaths in Canada was 47.9 percent (calculated from CIHI, 2021). However, given the high initial death rates among residents, followed by priority vaccination, the estimated number of “excess” deaths attributable to the pandemic was lower among Canadian seniors than the number of their directly attributable Covid-19 deaths, unlike the case for those under 65 (Statistics Canada, 2020, p. 4).

OWNERSHIP AND OPERATION

Considerable research and media attention has been paid to the impact of different forms of ownership and operation of nursing homes, both before and during the pandemic. This focus has been prompted by concerns that for-profit ownership is inferior in terms of quality and cost criteria. Academic studies undertaken before the pandemic showed that, for example, hospitalization and mortality rates were consistently higher among for-profit homes in Ontario (Tanuseputro et al., 2015). Systemic reviews of scholarly literature on this issue from other jurisdictions generally point in the same direction (Comondore et al., 2009; Hillmer et al., 2005; Xu et al., 2013). However, defenders of for-profit care have argued that these studies rely on observational evidence, which medical research considers to be of lower quality than the “gold standard” of randomized controlled trials. Yet randomized controlled trials of nursing home care are impossible, for obvious logistical and ethical reasons. In an effort to confront this catch-22 situation, Ronald and colleagues (2016) argue, with the careful use of Bradford Hill’s guidelines, that the link between cause and effect – or in this case between profit and care – can be a “reasonable inference” drawn from observational research.

Research and policy attention is increasingly focused on the PE and REIT ownership and operation of nursing homes, for two main reasons. First, their ownership and operation are increasingly complex and opaque, making regulation and accountability more difficult to achieve. Second, although resident populations now are older than they were in the past, with residents who are both frailer and have more co-morbidities than their counterparts years ago, their nursing home care is both measurably deteriorating and becoming more costly.
More specifically, PE and REIT involvement makes it much more difficult to track how these organizations siphon resources from care to profit in their homes, and therefore makes it much more difficult to confront. First, most PE and some REIT entities are privately held and are not required in any countries to report financial information to stock and bond exchanges. Second, many are formally based in tax havens that offer privacy for investors, away from the inquiring eyes of those who would expose where the profit ends up. Third, these entities typically consist of dozens or even hundreds of associated corporations, engaged in obscure internal transfers of funds. The Centre for International Tax Accountability and Research (CICTAR, 2021a, 2021b, 2022), a global research centre set up to untangle corporate tax webs, has conducted thorough studies of key international for-profit entities that own nursing home chains based in Canada (Revera), the UK (HC-One), and France (ORPEA) respectively, but it acknowledges that it does not present complete pictures.

Some of these corporations are “related parties” that may lend capital or lease facilities at above-market rates. They may apply above-market charges for financial or management “advice.” They may provide contracted-out services for any and all of the supplies, pharmaceuticals, therapy, physician, food, laundry, housekeeping, security, property and equipment maintenance, management, and of course the agency-based nursing and aides that homes need. Finally, when land and buildings are owned by an entity other than the home itself, the home may have no assets that are available in the case of lawsuits for malpractice. If such lawsuits are not feasible, the courts become a less useful tool for the discovery of where the profits end up, and for seeking remedy.

The US, UK, and France

Before analyzing the ownership and operation of nursing homes in Canada, Sweden, and Norway, I turn briefly to other jurisdictions. First up is the United States, where the PE and REIT situation is most pronounced and the research and media commentary on it are most developed. In the US, about 70 percent of nursing homes are owned by for-profit firms, with about 58 percent part of a chain (Kingsley & Harrington, 2022). Most of the large chains are owned by PE or REIT investors, leaving few that are publicly traded, and as a result there is little information on their finances available for independent analysis. By 2019, an estimated 11 percent of US homes were PE owned (Spanko, 2020), and the share has likely grown substantially since then (Gupta et al., 2021, p. 13). In 2021, an estimated 12 percent were REIT owned (Bruch et al., 2022). Precise percentages are difficult to determine, because sales and purchases are frequent, for reasons discussed below.
In England, the for-profit share of spaces in what are termed care homes is even higher, with over 80 percent of the spaces owned and operated by them. Only 13 percent are provided by the voluntary sector and a mere 3 percent by municipal councils (Campbell, 2019). With the ownership of buildings and land separated from the operation of care homes, two major providers (Southern Cross and Four Seasons), covering 45,000 residents, collapsed in 2011 and 2019, respectively. According to the Centre for Health and the Public Interest (CHPI), their demise resulted from having been loaded with heavy debts, rental charges, management fees, and other financial obligations by the PE firms owning the buildings and land. These and other large care home providers use complex company structures to hide profit extraction (Kotecha, 2019, p. 36). The leakage takes “the form of rent, dividend payments, net interest payments out, and profits before tax” (Kotecha, 2019, p. 4). By 2021, HC-One was the UK’s largest care home operator, with a reported 2020 operating loss of £12 million, along with about £42.4 million in interest and lease payments, mainly to related parties, and another £162.5 million in other expenditures to related parties (CICTAR, 2021a, p. 5), leaving residents and staff at risk.

Groupe OPREA, Europe’s largest long-term care operator, is headquartered in France, and “operates 1,114 care homes and other private medical facilities in 23 countries,” nearly half of which are in France and the Benelux countries (CICTAR, 2022, p. 9). In 2022, it was beginning to sell its property portfolio of €7.4 billion for speculative profits. With over 40 subsidiary companies in Luxembourg, as well as “platform companies” in Panama and the British Virgin Islands, it has an increasingly opaque corporate reporting structure. Its largest shareholder is the Canada Pension Plan Investment Board (CPPPIB), which owns 15 percent of its stock. Another huge Canadian pension fund, the Public Sector Pension Investment Board (PSPIB), is a major shareholder in Korian, ORPEA’s top French competitor. The PSPIB also directly owns Revera, one of Canada’s largest nursing home and retirement home chains (CICTAR, 2022, p. 6).

Canada

Revera features prominently in the Canadian picture. Unlike Extendicare and Sienna, two of its large competitors, Revera is “privately” owned, which is to say it is not traded on a stock or bond exchange. It thus does not have the legal financial reporting requirements that “public” firms do. As indicated, however, it is wholly owned by a pension fund for public sector workers, in this instance the civil servants, military, and police (Royal Canadian Mounted Police) employed by the federal government. The PSPIB is itself a crown corporation owned by the federal government. Like ORPEA and other major
chains, Revera is active beyond its host country borders, owning and/or operating hundreds of homes in the US and the UK under a variety of corporate names. For example, partnered with Welltower, the largest REIT in the US, it owns “5 retirement communities across Canada, US and UK” (Revera, 2022). With Welltower, it is linked to several “brands,” such as Sunrise, Gracewell, and Signature, in the UK and Luxembourg (CICTAR, 2021b). Overall, Revera owns 277 “communities,” of which 199 are in Canada, 45 in the US, and 33 in the UK. Its footprint in managing communities is largest in the US, where it has 226 of its “managed communities” and 23,500 of its 46,000 “managed units” or spaces for residents.

The totals for Revera, as for the other large for-profit chains, are only approximate, for several reasons. These entities may lack transparency in public reporting, they may combine nursing and retirement homes into a single category, and they may buy and sell homes to each other and manage each other. For example, in 2022, Extendicare acquired a 15 percent interest in Revera’s Ontario and Manitoba homes and took over the management of 32 more. By 2020, it owned or operated 122 nursing and retirement homes, and operated under other brands such as Extendicare Assist, ParaMed, Esprit Lifestyle, and SGP Purchasing Partner Network (Extendicare, 2020).

Extendicare Assist manages Orchard Villa in Ontario, a for-profit home that has arguably the worst record of any nursing home in the country. Neglect and even abuse of residents was documented by the Canadian military when summoned by the government to intervene at Orchard Villa during the pandemic (Brewster & Kapelos, 2020). Meanwhile, following a 2021 Saskatchewan government decision to sever its ties with Extendicare in the wake of a particularly horrendous death rate at one of its homes (Quenneville, 2021), Extendicare had to sell its five homes there. (It left the US market entirely after being sued in Florida and Texas in 2001, Kentucky in 2012, and eight states in 2014 following settlement of a $38 million case involving Medicaid and Medicare.)

While Extendicare was focused on nursing homes, management services, and home care, Sienna with its partner Sabra Health Care, a Maryland-based REIT three times its size, was expanding its retirement home holdings. It purchased 11 in Ontario and Saskatchewan from Extendicare in 2022 (Willis, 2022). It avoids new construction, preferring to pick up existing homes at 25 percent to 30 percent below replacement cost. It also manages 13 residences for third parties (Chong, 2022).

Chartwell, another of the large for-profit chains, is also selling its nursing homes in favour of retirement home growth. It recently sold 16 Ontario nursing homes to AgeCare, which owns nursing homes in Alberta and British Columbia, and Axium Infrastructure, a Montreal firm involved in highway and bridge construction and maintenance, as well as oil and gas. AgeCare is also assuming management of six additional homes that Chartwell has managed,
and two homes that Chartwell will continue to own. In an interview with the *Toronto Star*, Chartwell’s CEO is explicit about its strategic choices, opting “to fully focus on the ownership and operation of predominantly private-payer retirement residences” (Doherty, 2022). He draws a sharp distinction between nursing and retirement homes, noting that residents in retirement homes, which have more private suites, are generally healthier, more independent, and less prone to infection. Residents can also afford the private rooms and large amenity areas that retirement homes feature. In this interview as reported, the Chartwell CEO does not mention that retirement homes have the power to decide who to admit and who to discharge, as well as which services to provide and to what extent.

Schlegel, the fifth largest for-profit chain in Canada, is privately owned by a family. All its homes are located in Ontario. Some are managed by Extendicare Assist.

The largest for-profit nursing and retirement home chains have different strategic orientations, in Canada and elsewhere. They buy and sell the ownership and operation of homes with increasing frequency. They often separate the operation of the homes from the ownership of the land and buildings on which they are located. They have their own management services, which they sell to each other and occasionally to non-profit and public homes. They also contract out specific services, sometimes to related parties that they themselves own outright or control. They tend to be international in their reach, especially for tax avoidance reasons. According to a senior vice-president at a Canadian commercial real estate firm, unlike in other sectors such as industrial, apartment, and office assets, in seniors’ housing “the future demand is quantifiable.” And the rate of return on investment is double that of the other sectors (Lanthier, 2022). All these features make them challenging to regulate and hold accountable. As noted, prominent among their investors are huge pension funds, which may paradoxically be managing the retirement savings of public sector workers (Skerrett et al., 2017).

**Norway and Sweden**

By contrast with the United States, and with the United Kingdom and Canada, Sweden and Norway have long-standing social democratic traditions, and more often than not have been governed by coalitions led by social democratic parties. This has meant a heavy reliance on the public sector and on welfare state provision, rather than on insurance, coupled with a commitment to “service universalism” (Ågotnes et al., 2020, p. 38). Nursing homes are included in their welfare state regimes. Responsibility for and usually ownership and operation of nursing homes, rests primarily with municipalities. However, these and the other Nordic countries have been influenced to...
varying degrees by New Public Management agendas rooted in neoliberalism (Meagher & Szebehely, 2013). From the early 1990s, for-profit ownership of nursing homes increased from negligible to 18 percent of the total in Sweden and to 6.2 percent in Norway. In each country by 2017, about 70 percent of the for-profit share was held by four or five international chains. These chains also offered other health care, disability, addiction, and child welfare services. Three of the largest chains based in Sweden also operate in Norway, where they are among the largest (Ågotnes et al., 2020).

In Sweden, the social democratic party and the public sector union have until recently been ambivalent about neoliberal incursions, while in Norway they have been consistently opposed. One consequence is that in Norway, a potent NGO mounted a campaign called “For the Welfare State,” which has been prominent in preventing further incursions and in resisting them. In mid-2022 one of its leaders was appointed by the national government to a commission charged with investigating how for-profit entities could be phased out from various tax-funded welfare services.

Policy attention to, and resistance to, incursions into the nursing home sector have often been prompted by scandals unearthed and publicized by mass media. In Sweden in 2011, a scandal involving a Stockholm nursing home run by Carema, a for-profit chain, was first reported by the country’s largest newspaper. It exposed inadequate staffing by registered nurses (RNs), undernourished residents, unexpectedly high resident death rates, and insufficient supplies. A TV documentary revealed that Carema paid substantial bonuses to its managers for reducing costs, despite the impact on service quality. The effect of these media stories was to place for-profit ownership on the political agenda. Government ministers from the Conservative and Christian Democrat parties announced investigations into the exporting of profits by international PE firms (Carema had been sold by a British PE firm to an American one in 2012), the monitoring by municipalities of care providers, and public/private quality differences. The municipality in Stockholm responsible for nursing home funding ended its contract with Carema (Lloyd et al., 2014).

In the same year in Norway, the state-owned national broadcaster revealed systematic violations of workers’ rights at an Oslo nursing home operated by Adecco, a Swiss for-profit PE corporation. Staff were housed in an on-site basement bomb shelter, working up to 84 hours a week without overtime pay. Later stories revealed that at other Adecco homes, staff lacked valid contracts, lacked holiday pay, worked up to 20 hours a day for 100 hours a week and for 20 consecutive days, and saw Adecco holding onto their pension deductions. Adecco retained fewer RNs and auxiliary nurses than specified in its contract with at least one municipality (Lloyd et al., 2014). The four major Norwegian cities, Oslo, Bergen, Tromso, and Trondheim, all ousted for-profit firms from their municipalities in 2015. A year later so did Moss, a smaller community,
which ended its contract with Norlandia, a for-profit firm, following reports of neglect and deaths. Adecco was forced to withdraw from the health and care sector in Norway, although it retained contracts in other industrial sectors such as employment agencies and slaughterhouses (Harrington & Jacobsen, 2020).

An analysis of government responses to nursing home scandals in five countries (Canada, the UK, the US, Sweden, and Norway) showed significant jurisdictional differences. Sweden and Norway addressed “underlying structural conditions” (Lloyd et al., 2014) but that was not true of the other three countries. Rather, in Canada, the UK, and the US the new regulations prompted by the scandals focused on carrying out closer supervision of staff. The underlying structural conditions remained the same. In the Scandinavian countries, the land and buildings are almost all publicly owned by the municipality concerned. In the other three countries, the land and buildings tend to be owned by a for-profit entity. When only the operation of the home is for-profit, it is much easier to terminate for-profit involvement by ending the contract and either assuming direct operation or, as is occasionally done, turning over the contract for the facility to another entity, a non-profit one. This can be accomplished at the end date for the contract or even while it is still in force, if contract provisions have been sufficiently violated. In either case, access to the land and buildings remain stable. No resident is forced to seek another nursing home. The opportunity this situation creates for reducing profit in the nursing home sector is taken up in the section that follows.

PROSPECTS FOR RESISTANCE

Annemarie Mol (2008) eloquently contrasts the logic of care with the logic of individual choice, which she regards as neo-colonial ideological violence when viewed from, say, West Africa. For Mol, good care does not follow from (the false promise of) creating more avenues for patient choice. In the industrialized world under consideration here, the logic of care must be juxtaposed to the logic of capital.

The dismal track records of for-profit care in nursing homes during the Covid-19 pandemic serve to intensify political debate and strengthen the public’s resolve to eliminate it. The question becomes how can we achieve this elimination? The answer is complex and difficult. Context is a key consideration. In different jurisdictions are to be found different histories of for-profit presence, different types and degrees of regulation, different tax regimes and levels of enforcement, and different political institutions and cultures. On this last point, in Norway and to a somewhat lesser extent in Sweden, political parties, unions, and NGOs have played pivotal roles in resisting the penetration of for-profit firms. In both countries, robust investigative print and broadcast journalism has also played a key part.
In these Scandinavian countries, the tradition has been, and remains, to keep the land and buildings in public, usually municipal, hands. This is perhaps the most straightforward way to bring nursing homes into the public or non-profit realm. When the contract with a for-profit licensee runs out, or even before, if the contract has been sufficiently violated, operation can be transferred to another entity relatively seamlessly. Elsewhere, however, the public sector has unfortunately been busy subsidizing the capital costs of for-profit firms in various ways. The REIT and PE owners seek quick profits from real estate. Land is often assembled and buildings constructed through public-private partnerships (P3s), at great long-term cost to the public purse and with the land and buildings belonging to the partnership when the agreement ends after 20 or more years (Whiteside, 2016). In the UK these partnerships are usually known as Private Financing Initiatives (PFIs). As of 2018, there were 127 PFI schemes in British hospitals and social care facilities, with a capital value of £13 billion (Kotecha, 2018). A substantial literature in several countries has for years documented their negative effects over the long haul on costs to the public, and on quality, access, and accountability (see Pollock, 2004, pp. 52–57).

Where the land and buildings are not in public hands, eliminating profit from nursing homes is decidedly more difficult. The vested interests involved in maintaining the status quo, which include some of those whose savings are invested in pension funds, are powerful. Pension funds themselves are frequently in partnership with other PE entities, and may be reluctant to reveal much about their transactions (Robertson, 2022). In Canada, some workers and their unions, especially in the public sector, are mounting pressure to have their pension funds dis-invest from nursing homes, but they run up against contradictions imposed by regulations of fiduciary duty, the duty of the board and management to give priority to profit-making (Skerrett et al., 2017), a financialized view of worker self-interest, and more generally efforts by capital to obfuscate any and all efforts by environmental, social, and governance (ESG) movements to require corporations to attend to ESG concerns in their pursuit of profit (Bakan, 2020). A “Make Revera Public” campaign was launched before the 2021 Canadian general election with 17 federal public sector unions led by the Public Sector Alliance of Canada and with support in numerous communities where Revera homes have experienced resident deaths. It failed to have much impact on the 2021 election. This was even though the ownership of the PSPIB rests with the federal government and is thus subject to some public scrutiny.

Finding out about the ownership and operation of nursing homes, a first step in getting rid of profit, is even more challenging in the many cases without direct public sector involvement. It can require identifying dozens or even hundreds of “related parties” and other (hidden) firms from the top to the bottom
of each cluster of firms, and overlapping clusters of them as well. They own,
control, manage, lend to and borrow from, and supply each other. Tracing links
to dummy corporations in tax havens may be required.

To achieve accountability to the public, which pays most of the costs and
has a responsibility to protect its vulnerable nursing home residents and their
staff, the first demand then is for the full disclosure of these many connections.
This is particularly difficult to achieve when REIT or PE financing is involved.
For example, as a PE firm in Canada, Revera reveals little at home about its
connections. It has, however, established a close relationship with Welltower,
the third largest REIT in the United States, providing us with some insight
into its operations. Over one-fifth of Welltower’s total operations are managed
by a Revera firm. Together they also control Sunrise, which is another large
seniors’ home operator in the US that is also active in Canada and the United
Kingdom. A simplified depiction of the Revera-Welltower-Sunrise structure
lists over 20 firms under other names that are operating in the UK and in the
US, Luxembourg, and Jersey. Welltower also has a majority interest in 39
Chartwell properties in Canada (CICTAR, 2021b).

Large “related party” loans provide the leverage for aggressive purchasing
strategies by large chains. They use the assets of the homes they purchase
as collateral for their borrowing, then require the homes to pay off the debt,
perhaps at above-market rates. In this and other ways, the homes themselves
may appear to show no profits or to be losing money. This is beneficial to
the homes, as they appear not to be extracting profit from the care needed by
vulnerable seniors. The profits are often shifted to tax havens, which are jurisdic-
tions where they are subject to scant scrutiny and little if any corporate tax.
The second demand, then, is for full disclosure of the financial flows among
associated companies. A related demand is for the enforcement of tax policy
to ensure that taxes are properly paid in the jurisdictions in which the profits
are generated.

Contracting out the purchase of specific goods and services, whether to
“related parties,” enabling the siphoning-off of profits, or to other entities, is
a device for avoiding responsibility and liability. It can also have a negative
impact on quality. It is often claimed that the practice of contracting-out lowers
costs, but this is unlikely over the longer term, once the contractor has settled
in. This claim also ignores the transaction costs involved in negotiating a con-

Another challenge is that for-profit companies tend to hire fewer, some-
times lower-qualified, staff and pay them less. Again, this is a matter of
establishing and enforcing appropriate staffing standards that are transparent
and adjusted to take account of the needs of residents, and of staff. Having
enough well-trained staff has long been a demand (see Harrington et al., 2000),
but became intensely obvious during the disastrous pandemic experiences in
Piercing the corporate veil

nursing homes. Yet again, full public reporting is needed (Marrocco et al., 2021, pp. 235–236). The reports must count who actually does the direct care work, excluding those paid but not at work for vacation, sick leave, and other reasons, and excluding those who supervise or record work activities.

The challenges are daunting, but there have been some successes. And public attention is being increasingly focused on the need for reform. In the United States, the White House announced in February 2022 the administration’s intention to improve transparency of nursing home ownership and finances, to examine the role of PE and REITs, and to establish a minimum nursing home staffing requirement (White House, 2022). Also that year, the National Academies of Sciences, Engineering and Medicine in the US issued a report on the imperative to improve nursing home quality, with a focus on financing, transparency, and accountability in funding and payment (Werner et al., 2022). In the United Kingdom, six options for dealing with the negative legacy of PFIs have been thoroughly set out (Kotecha, 2018).

More concretely, the Norwegian case has already been mentioned. Private chains have been almost entirely pushed out. In the United States, the Affordable Care Act requires the electronic reporting of direct staffing information based on payroll and other auditable data, although as elsewhere the tighter requirements give rise to more innovative gaming responses. New California legislation and regulations require each home’s operating company to provide consolidated financial reporting on each of its entities, including contracted firms. Additional strategies are discussed in the chapter on accountability in this book.

To conclude, it is difficult to “pierce the corporate veil,” that is, hold owners responsible for the actions of a corporation, as a journalist found when probing Brius, a particularly bad California nursing home chain (Rau, 2018). A telling Canadian example of the difficulty was inadvertently exposed by an ostensibly “outside expert” group that issued a report on Revera, claiming on the basis of its “unusual access” that factors other than its own practices were responsible for the many Covid-19 deaths among its residents (Abraham, 2020). What is usual, however, is corporate secrecy. What is unusual, if welcome, is that firms like Revera are occasionally put on the defensive. Meanwhile, across North America, REIT and PE chains are increasingly investing in land and buildings. Ontario is selling government land across the province to private developers for the construction of new nursing homes. Firms such as Arch Corporation, which has backing from Middle Eastern capital through the Gulf Cooperation Council or GCC, buy homes and then hire outside management firms to provide the care. They aim to “generate stable long-term cash returns.” As the CEO for the CanAge organization puts it, “You can’t blame private equity … [for squeezing] every signal dollar out of what they invest” (Welsh, 2020). Operators can contract-out everything, from management services to
purchasing to food and laundry to maintenance to staffing agencies to therapy, reducing their liability further in the process.

To continue pressing for the elimination of for-profit firms, and most notably those organized using REIT and PE financial tools, will be a long and difficult road to travel. Here are some major steps to take on down the road.

1. Establish public ownership of the land and buildings where nursing homes are located.
2. Require full transparency of the ownership and operation of each home.
3. Require full transparency of the financial flows among “related parties.”
4. Enforce the payment of taxes in the jurisdiction in which each home operates.
5. Eliminate contracting-out, whether to “related parties” or to independent providers.
6. Require full and regular reporting of who actually does the direct care work in each home.

Success in removing profit from nursing homes will serve residents, staff, and societies in general. With support from robust NGOs and probing investigative journalism by mainstream print and electronic outlets, there are ways forward.

NOTES

1. See, for example, Sadri and Fraser (2022), drawing on a 1952 series in Maclean’s magazine by Sidney Katz.
2. International comparisons are imprecise because definitions, methodologies, and timelines differ somewhat. The broad picture is incontestable, however.
3. For some purposes, Revera and other chains draw a sharp distinction between nursing homes and other forms of congregate living primarily for seniors, such as what are termed retirement homes in Ontario. For other purposes these forms are blended together, as in the Revera website and most Statistics Canada reports.
4. A Canadian news item recently revealed that the PSPiB sold $2 billion of its $35 billion stake in PE. The PSPiB declined to comment publicly for the item, but the business press did draw attention to the growing second-hand sales of PE stakes, as some investors seek to cash out early from capital that is locked up for years (Robertson, 2022). There are of course frequent ownership changes among the chains themselves in the homes they control.

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3. What’s critical to care?

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Covid-19 made it clear that nursing homes are where some of the most vulnerable people live. Not surprisingly, the response to the high infection and mortality rates in nursing homes was almost exclusively focused on physical vulnerability. Infection control, medical care, and treatment were the priority even before the pandemic. When Covid hit, residents were isolated in their own rooms or at least strongly advised to do so while families and friends were excluded from entering the building. These strategies meant many residents survived for another day. At the same time, however, an analysis of European responses to the Covid crisis (Curry & Langins, 2020) found that banning visitors for residents was “detrimental to their well-being.” Some, in Canada at least, suffered badly from the neglect of other aspects of care, such as assistance with eating, drinking, or going to the toilet (Mialkowski, 2020). Meanwhile, all high-income countries scrambled to fill Covid-caused staffing vacancies in ways that focused primarily on numbers rather than on the care of workers.

Covid allows us to once again revisit what we mean by nursing home care and what is critical to that care – and to ensure that care will be there, not only to support survival but to allow people to thrive. Our starting assumption is that care is a relationship that builds on strengths and attends to individual needs. Care relationships are complex, requiring considerable skill, information, and structural supports to develop and maintain. They involve multiple competing demands and tensions, complicated by inequities in power and in continually evolving capacities. For us, everyone who lives in, works in, or visits nursing homes is involved in care relationships, for good or ill. This means that we need to understand these places as both work and living spaces, as well as organizations that provide medical, social, and living supports. It takes the village that is the nursing home, and the community in which it is embedded (Ågotnes & Øye, 2018), to appropriately promote such relationships.

As is the case with other chapters in this book, we draw on more than fifteen years of research on and in nursing homes. We have studied care homes in Canada, Germany, Norway, Sweden, the United Kingdom, and the United
States. Our multiple methods have included team ethnographies that provide rich interview and observation data (Armstrong & Lowndes, 2018). Based on these data, we identify some central ingredients and tensions to be balanced in promoting nursing home care relationships. Because we assume that contexts and diversity in populations matter, we are not primarily searching for single best practices or models but for ideas worth sharing in treating residents, staff, and families with dignity and respect. Like a manager we interviewed in Germany, we focus on putting life into years rather than years into life.

RISK TOLERANCE

Residents want to be safe. Families want their relatives to be safe. Staff want to keep residents and themselves safe. Management and governments have a vested interest in keeping them all safe, especially when scandals about unsafe care and conditions appear in the media (Lloyd et al., 2014). Although it is always an issue, safety from infection became the primary concern in the early stages of the pandemic when it hit the care home population hard. Many countries scrambled to find personal protective equipment (PPE) and hand sanitation materials. And they scrambled to develop strategies that would keep as much distance between people as possible and as much Covid out of care homes as possible.

Such approaches were important in controlling infection, especially before we learned more about the ways Covid is spread and before vaccines became available. But they also highlight how a focus on safety alone has negative consequences. Indeed, the isolation of residents that resulted from the focus on safety may even kill. A Canadian study found that the death rate was higher among residents who had no family or friends to contact them and no way to leave the home to make contacts or just walk around to see people (Savage et al., 2022).

In fact, risk avoidance pre-pandemic had harmful consequences. For example, in many of the Canadian homes we studied, fear of falls leads them to put too many residents in wheelchairs on admission. We were told by more than one family that their relative walked into the home but was soon confined to a wheelchair and, as a result, could no longer walk alone. In those homes, managers said that all falls are taken as a critical indicator of quality and may generate poor scores on the widely used reporting system (Armstrong, Daly, & Choiniere, 2016). In any case, they did not have enough staff to walk with residents, and insurance companies required strict risk avoidance. We saw many more examples of risk intolerance, with prohibitions against things such as salt and alcohol, and against the use of such things as kettles and knives, while pureed food was provided for the majority and personal laundry was boiled to
kill germs. At the same time, we studied homes that did none of these things, without major health consequences (Chivers, 2017).

Our fieldnotes indicate more risk tolerance in a Norwegian nursing home. For example, an occupational therapist who was strongly encouraging a frail resident to walk explained that it is her job to push people to the limits of their capacities so they can keep those capacities as long as possible. Only falls resulting in serious injury are reported, while there are continual assessments among staff about balancing the tension between risk of falls and loss of capacities. However, research by Norwegian members of our research team uncovered multiple, less visible forms of limits on “residents’ freedom of movement and their personal preferences.” These include “(1) diversion of residents’ attention; (2) white lies; (3) persuasion and interpersonal pressure; (4) offers and finally (5) threats” (Øye & Jacobsen, 2020, p. 187). The reasons for their use related to “organisational conditions such as resident mix, staff culture and available human resources” (Øye, Jacobsen, & Mekki, 2017, p. 1906). While any or all of these less visible forms of restraint may be appropriate and effective for particular residents at particular points in time, they illustrate the tension between resident autonomy and safety and the need to think carefully about their application (Armstrong, 2018).

To paraphrase Gawande (2014), life without risk is boring. In assessing risk, we must also consider the ways risk avoidance can undermine a life worth living. Staff in an Australian study said that “there is a fine line between giving residents options and allowing residents to act against what they considered in the residents’ best interests” (Garratt et al., 2021, p. 3130). But in drawing that line we must be careful about who defines best interests, what factors are taken into account, and whose interests matter.

CARE FOR LIVING

Medical care is essential, and increasingly so as more residents have complex care needs. The families and residents we interviewed were relieved that medical issues received skilled attention, although many also stressed the need for a different kind of medical care. They, as well as staff, wanted a physician and/or a nurse practitioner employed full time – rather than part-time ones who dropped in for short periods – so the medical providers would know both the residents and the staff (Banerjee et al., 2018; McGregor, 2016). They also wanted more staff to have medical skills and, in the wake of Covid, infection control experts on the team, along with infection training for all.

In Norway, we heard and saw how important it is to integrate palliative care into daily practices, recognizing that a majority of residents die within eighteen months of entering a care home. At the same time, a significant number of residents live for many years in the care home so palliative care is
What's critical to care?

only one kind of medical care required. Across Canada, we were told about the over-reliance on antipsychotic medication (Chiu et al., 2015; Lexchin, 2013) and the tendency to treat all issues as medical issues. Instead, many families and residents told us they wanted fewer medical indicators, such as constant call bells and medical carts in the halls, and more signs of active living. They also wanted more alternatives to medicines, such as music therapy (Baines, 2019), and more alternatives, such as continence training, to practices like the standard use of incontinence pads as well as more accommodation of cultural differences and attention to gender issues. (Armstrong, Armstrong, & Daly, 2012).

But medical care is only one critical component in long-term care. Like Johs-Artisensi and Hansen (2022), when we talked with residents and families about what had the greatest impact on their daily lives, food and the entire dining experience were near the top of the list. In our research, so were clothing, laundry, clean bodies, and clean environments (Müller, Armstrong, & Lowndes, 2018).

As we saw in the homes we studied, food is about much more than ensuring nutrition (Lowndes, Daly, & Armstrong, 2017; Lowndes, Armstrong, & Daly, 2015). Mealtimes are often the main events of the day. They offer an opportunity to socialize and to move into a different space. Visually attractive, culturally appropriate food with texture, colour, and pleasing smells, served at flexible times and in chosen amounts, with companions of your choice and assistance when needed, provides pleasure and stimulates appetites. However, often in Canada we saw rigid time schedules, full, colourless plates, main courses and desserts served at the same time and temperature, while food was quickly fed to those who needed assistance. In homes with privatized food services, meals were often prepared off site and offered no tempting smells or sights, and contracted staff had no opportunity to know resident tastes. In Norway and Sweden, there was at least more flexibility in timing, and food was prepared on site, if not in the unit. In those countries, we saw places that put full dishes on the table, to be passed around by residents just as they would at home, while still recognizing that staff must be there to assist, especially for those with dementia. We also encountered creative chefs, like the one in England who offered appetizer-sized options to tempt appetites (Braedley & Armstrong, 2017). When he took this inventive initiative, nutrition levels went up. In a Canadian home, the chefs brought the food from the central kitchen on warming carts, offering residents choices about what and how much they wanted, in the process getting to know the residents and their preferences and avoiding full plates of wasted food sent back. In this home, the chefs had co-designed their bright, spacious kitchen. In another Canadian home, the same basic ingredients were used to produce culturally appropriate food at each meal to accommodate the diverse population. In some homes in all the
countries we studied we saw separate dining rooms that allowed families and residents to eat together or that could be used by residents who were friends or had similar interests and capacities (Daly, 2016).

Although food is receiving some attention, it is less the case with clothes. Yet clothes are critical to dignity and respect – an indicator of identity and of a self separate from being a “resident” (Armstrong & Day, 2017). Enough space to store a range of clothes and a means to have them safely washed, along with assistance in allowing residents to select their clothing and dress themselves as much as possible, are basic to care. In Sweden, for instance, we saw hooks near the door for outdoor clothing, indicating possibilities for engaging in activities outside, and in the US homes we studied, residents had enough closet space to allow variety in their daily dress. The generous closet space and clothing choices available in Germany were evident in our field-notes. Residents “are wearing fitted, quality skirts, i.e. pleated dress pants, cardigans and collared blouses. Clothes match” (Armstrong & Day, 2017, p. 139). Hair was carefully combed, buttons done up, and women often wore jewelry and makeup, carefully applied. In contrast, some Canadian homes provided lists of the limited amount and type of allowed clothing, stressing things like track pants and materials that could be boiled. Jewelry of any kind was often discouraged on the grounds that it could be stolen or constituted a risk.

Equally important are adequate linens and the means to quickly remove soiled items, in ways that avoid smelly carts in halls and heavy wet laundry loads dealt with by staff labouring in windowless basements. Some homes we studied in Canada had separate rooms on each floor dedicated to storing soiled linen in ways that kept them out of sight before being removed to a centralized service. Some had domestic-sized washers and dryers in each unit that could be used by staff, families, and residents for small loads. In Sweden, we saw a washer/dryer combination in each resident’s bathroom. Staff – or the resident if they were able – could put in small loads and adjust for particular fabrics, hanging the most delicate materials to dry. This not only prevented the resident’s favourite sweater from shrinking or getting lost (complaints we often heard in North America), but reduced injury and infection spread. It contrasted sharply with a Canadian home that had privatized laundry services delivering clothing on racks stored in the hallways. Residents often thought these were places to shop, taking clothes that did not belong to them.

The pandemic made the need for a clean environment a high priority everywhere. But clean is critical in nursing homes all the time, given residents’ compromised immune systems and frailty that contribute to spills and other messes that pose trip hazards. Cleanliness is not only about safety, but about creating a pleasant living environment (Braedley, 2016). However, a focus on cleanliness often means vinyl and other hard, washable surfaces and heavy cleaning equipment blocking halls, aspects that make a place feel cold and institutional.
Yet in homes in both Canada and Sweden, we saw washable cloth slipcovers used in sitting areas to create living spaces, accessible storage spaces for cleaning materials and easily replaced carpet squares to address spills or, even better, low-impact linoleum in soft colours or non-slip hardwood.

Clean requires equipment that is safe and easy for staff to use, without toxic ingredients or chemical smells. In Sweden we saw light, efficient cleaning equipment that fit easily into confined spaces. It was designed after consultation with staff who knew intimately what was required. Similarly, in Canada staff told us they developed colour-coded cleaning cloths to prevent cross-contamination and, like their Nordic counterparts, fought for more environmentally and worker-friendly cleaning materials. In some places, especially in Canadian homes that have outsourced the housekeeping services, cleaners are told to avoid entering rooms when residents are present and to move out of the rooms as quickly as possible. In contrast, residents and those doing the cleaning work in many homes told us they enjoyed their conversations with each other, taking time to establish rewarding relationships during the cleaning.

And, of course, residents also need to be clean. Body care is necessarily intimate. A manager in a Canadian home we studied had new staff bathe each other so they could understand the vulnerability in being bathed by others. Bodies can require not just daily but often hourly attention to prevent infection, sores, and discomfort. Bathing can be a calming, pleasurable experience, but too often bathing is rushed, with little attention to dignity or comfort, and too often provided on a rigid schedule, especially in North America. Like dining and dressing, bathing takes time, equipment, skill, teamwork, and appropriate supports. In a Swedish home, for example, the staff discussed how they could convince a former diplomat with dementia to have a shower. The effective strategy they developed was to knock on her door and announce, “You have booked a bath, I am here to help you with that” (Braedley & Szebehely, 2017, p. 78). Our fieldnotes from a Norwegian home describe:

>a therapy pool that is wheelchair accessible, meaning you can take the wheelchair in the pool. It is kept warm … and is used for therapy we are told. It is good for stroke, cancer, and other conditions. Babies from the community also use it … We are then taken to the ward and shown the bathtub rooms, which they have turned into a spa. It smells strongly of melting candles and there are candles lit everywhere on beautiful glass holders. White robes, blue towels, aroma therapy sticks, little touches that make it feel like a spa. I am immediately soothed by the environment. (Choiniere, 2016, p. 48)

Body care also includes oral care and toilet assistance. This care too may be rushed or rigidly scheduled in ways that cause not just discomfort and indignity but incapacity and poor health (Yoon et al., 2018). Too often, essential
body work and comfort are missed. In our pre-pandemic survey of Canadian and Scandinavian staff (Armstrong et al., 2009, table 14), only a quarter of the Canadians said tooth brushing was never left undone, while nearly half said this was the case with bathing. And there may be no time for a soft pat on the back. Touch, as long as it is undertaken in a culturally and gender-sensitive manner, is an important source of comfort that cannot be replaced by a robot (Lanoix, 2018).

Residents not only need to be clean, fed, and dressed: they also need stimulation, and engagement that includes but goes beyond formal classes and group activities. Activities integrated into daily life were particularly appreciated by residents we interviewed. We saw staff stop in the middle of mandated tasks such as medication rounds to sing, dance, or just chat with residents and we saw staff encourage residents to assist in meal preparation, cleaning, and dishwashing (Lowndes, Struthers, & Ågotnes, 2021). We also observed volunteers from community organizations coming into the home to do everything from providing Japanese tea service to bringing in their babies to be cuddled. Dogs often offered the opportunity to engage in ball throwing that was more interesting than tossing to other residents. A coffee shop in a Swedish home that was integrated with a student residence offered the opportunity for intergenerational, spontaneous interaction. And we saw residents moving out into the community, engaging with others or simply enjoying being part of the scene outside the home on their own. In Norway, a resident choir that included many who were primarily non-verbal performed for the public. In this same home, the dining room offered low-cost meals to people outside the home, simultaneously providing company for those in both kinds of communities.

Congregate care can offer opportunities for social exchange and the comfort of being part of a community inside the home. When we asked residents in Canada what was good about long-term care compared to a private home, we often heard “we have company,” and like Swedish residents, they felt it was “nice to sit and eat together with others.” Often called social care, providing emotional, psychological support, and social connections are understood to be part of paid care. Long before the pressures of Covid, we asked direct care workers in Canada and Scandinavia how often they sat down to have a coffee or tea with a resident. More than half the Canadians said they rarely or never did, while this was the case for less than a quarter of the Norwegians (Armstrong et al., 2009). In our interviews with families, residents, and staff, we heard again and again about the lack of time to chat, explain, share stories or comfort. At the same time, we heard about how rewarding the social connections are for staff as well as for residents. As one Canadian RN put it, “I’ve heard so many things that I would not have heard anywhere else … from speaking to residents … Their former history, things like that … It is rewarding” (Armstrong et al., 2019, p. 8).
We frequently observed residents and families offering company and social support to each other. They chat together and walk together, sharing experiences and family stories. However, not all residents are pleasant to be with, and few residents want to be with others all the time. Opportunities for privacy are also important, not just in terms of having your own room and bathroom, which is the case for most residents in Sweden and Norway, but in terms of places within the home to quietly read or just be alone or with a friend. Privacy is also important to sexual pleasure (Daly & Braedley, 2017) and to safety, not just in terms of infection but in terms of other risks such as wandering residents. Like the other tensions in care, the tensions between loneliness and being alone, between privacy and risk of harm – as well as those among staff, families, and residents related to these issues – need to be recognized and balanced.

Comfort and company from staff, residents, and families are particularly important when a resident is dying and after a resident’s death. We studied homes in Canada, the US, and the UK that tried to send dying residents quickly to hospital. Some also hastily removed the dead, often out the back door, without telling residents, staff, and non-related families. More than one resident told us that they “didn’t want to be put out with the garbage.” We also studied homes, like one in western Canada, where the manager said, “We really don’t want them to leave, to go anywhere to die. They should die at home with the people who love them and care for them” (Zinnick, Struthers, & Doupe, 2017, p. 111). Our fieldnotes in another Canadian home reported that the “management/staff encourages their families to come and stay overnight in the family room but also volunteers are sitting with the residents” (Banerjee & Rewegan, 2016, p. 97). In Norway, Sweden, and Germany, we were told they ensured dying residents are not left alone. There were memorial services and hearts on doors of residents who have died, and time as well as space allocated to allow staff, residents, and families to grieve. In all the countries, we observed draped caskets carried out through an honour guard of staff to the front door.

Not surprisingly, risk avoidance and medical care became care priorities during the Covid pandemic, especially before vaccines. At the same time, the limited attention to the ingredients necessary for some quality of life made their importance more obvious. These ingredients can be addressed in a variety of ways, but they need to be addressed. All of them involve trade-offs and tensions, especially when the majority of residents have some form of dementia and many have limited physical capacities. Families, residents, staff, management, and governments often disagree about what is appropriate, and interests can collide, leaving few single best practices. However, as our research and that of a growing number of others shows (see, for example, Gilbert et al., 2021), there are some critical structural and organizational components that are essential to putting life into years.
MAKING CARE POSSIBLE

Risk tolerance, medical, body, and social care, food, clothes, and housekeeping – indeed all aspects that contribute to making life worth living – depend on having enough staff, with appropriate training, and with the working conditions that allow them to apply their skills, as well as stay in the job (see Chapter 4). As we have long argued, the conditions of work are the conditions of care (Armstrong & Armstrong, 1996).

Long before Covid, it was becoming clear that staffing levels were too low in care homes. As we heard so often in North America and the UK, there are “not enough hands.” Almost two decades ago, research conducted in the US included time-motion studies to measure how many minutes it takes to cater to a limited list of residents’ essential needs in a given day. This research led to a call for an enforced standard, setting the minimum staffing level at 4.1 hours of nursing staff per resident per day, with at least .75 registered nurse hours per resident per day (Centers for Medicare and Medicaid Services, 2001). It should be noted that this number is for direct care staff only and for those actually present. Multiple studies since then have documented the increasing frailty of residents, which means that even higher staffing levels are required just to meet residents’ basic needs (Harrington et al., 2020).

According to 2019 OECD data (2021), Norway, followed closely by Sweden, has the highest number of long-term care workers per 100 people over aged 65, with 12 and 11 respectively. The US has 6 and Canada trails with 4 per 100. In all these countries, the overwhelming majority of those counted in these data work in residential care rather than in homecare. Since 2011, their numbers have been declining relative to the growth in the older population. Hidden in these data are the growing numbers in all four countries who work on a part-time or casual basis, further reducing the hours of care.

But numbers alone are not enough. It takes skill to provide care, especially as the complexity of needs grows. That a third of the Norwegian care home labour force is Registered Nurses, compared to 8 percent in Canada and 6 percent in Sweden may help explain why Norway had lower Covid death rates in their care homes (Swedish Agency for Health and Care Services, 2021). However, especially in Canada and the US most of the work is done by women with little formal training, which helps account for the assumption that this is work any woman can do by virtue of being a woman (Armstrong, 2013). The European Commission (2021, p. 68) reports, in what our research indicates is an understatement, that long-term “care jobs are often more complex than their public image suggests.” Even the skills required of nurses are often dismissed, with the assumption often reflected in their lower pay compared to hospital nurses. Yet as a Canadian nurse explained, “I think the stuff we have to do calls
What’s critical to care?

on so many aspects of nursing that would blow a hospital nurse’s mind. I really do” (Armstrong et al., 2019, p. 12).

Indeed, all of the work requires skills – skills that change as the needs of the residents individually and collectively change (Barken & Armstrong, 2017). Bathing a fragile resident with dementia and Holocaust memories is no simple task, nor is assisting that person with eating when they have no teeth, trouble with swallowing, or no appetite. Those doing housekeeping work need to know how to manage around a person with dementia, how to clean up dangerous spills and deal with linens full of waste. It takes more, though, than skills acquired formally or informally.

It also takes leadership and organizational structures that provide staff with the autonomy to apply their skills to individuals’ needs and capacities (Bourgeault et al., 2021). Various cultural change models all make leadership central to resident and staff health (Armstrong et al., 2018). Covid emphasized the need for leaders who regularly support, communicate, and consult with residents, staff, and families while keeping up with the latest developments in science (Havaei et al., 2021). Before Covid, a manager in Germany explained:

[We] attach great importance to well-being of the residents but also have the same focus on staff. Only if staff is happy can they offer the same to residents ... staff is the major capital and [we] base policies on this in order to be able to perform good care. (Choiniere, 2016, p. 51)

Central to the organizational and leadership structures necessary for employing skills is the promotion of both continuity in care and teamwork. As a personal care worker puts it, knowing a resident over the long term “helps you to care for them because you get to know them on a different level and you get to know exactly what their needs are and how to approach them when it comes to certain things.” It is also “one of the best, what I mean about the residents, the connections you build; of course, with the staff too” (Armstrong et al., 2019, p. 8). Staff can support each other and share knowledge. According to a nurse, “when you also work as part of a team, you know it makes life more joyous in a nursing home, if you all get along especially” (Armstrong et al., 2019, p. 10). Teams, in turn, need and support flexibility in the division of labour, of the sort we saw in Sweden (Daly & Szebehely, 2012). Such teams include the entire range of staff, recognizing they are all critical to care. As Chapter 4 explains, increasing part-time, casual, and contracted work undermines the necessary continuity of teams and increases inflexibility. Even in the Canadian context, where there is a less flexible division of labour and a higher reliance on part-time staff, one manager ensured that all staff were employed full time or permanent part time. When a vacancy in a full-time position became available, she hired from among the permanent part-time staff to ensure continuity. The
receptionist delivered menus to each resident every day to ensure she knew all of them and the laundry workers returned laundry to individual resident rooms, chatting with residents while they put clothes away.

Full-time, skilled staff working in teams supported by effective leadership and appropriate compensation are critical to providing responsive care. But more is needed to ensure that care homes are accountable (see Chapter 10). As research by our team indicates (Lloyd et al., 2014), the primary North American response to scandals has been more, and more detailed, regulation of workers, as well as more counting of tasks completed, but there has been little attention to regulating larger structural issues or to ensuring broader participation in decision-making (Banerjee & Armstrong, 2015).

Means for participation go beyond the staff, allowing the sharing of expertise and ideas for improved care. In one Canadian province, all homes are required to have residents’ councils and family councils are allowed; but such councils are not common in the other countries we studied. Although many of these councils function mainly as places for management to provide information, they offer the possibility for greater influence. In interviews we conducted during the pandemic, we heard about both kinds of councils becoming more active. The councils demanded better communication and more involvement in how homes responded to the pandemic, rejecting multiple choice surveys as a primary means of participation (see Chapter 8). In Norway and Sweden, the designated care worker provides individual families and residents with a way of obtaining information and influencing decision-making in their particular case. Governing bodies too need to be structured to ensure ideas from staff, residents, and families influence decision-making, and members of such bodies need to be better educated about the skills required and conditions involved in long-term care. We did not see any places where this was the case. Nor did we see many examples of effective broader public accountability. In Sweden and Norway, where municipalities are primarily responsible for care homes, decisions are made closer to the communities in which they are located. However, here too there are tensions. As Covid demonstrated, this decentralized structure made it more difficult to employ national strategies (Swedish Corona Commission, 2021).

There are multiple other factors that shape the possibilities for care. The physical environment discussed in Chapter 5, the ownership patterns considered in Chapter 2, and the regulatory framework explored in Chapter 10 are important factors. Financing also matters. The significantly higher public investment in Swedish and Norwegian care homes helps to explain why the majority of people in Sweden would prefer to go into a nursing home if they required homecare several times a day (Szebehely & Meagher, 2018). This contrasts markedly with the situation in Canada, where nine out of ten Canadians would avoid care homes if at all possible (Herhalt, 2021). But it
What’s critical to care?

It takes more than money. It begins with seeing care homes as places to live, work, and visit, and what is required to support them, including integration with the community in which they are located (Struthers, 2016). It includes understanding that care is a collective responsibility for public good rather than for profit (Armstrong & Armstrong, 2020).

**CARE HOMES AS GOOD AS THEY CAN BE**

The pandemic offers an opportunity to rethink nursing homes, beginning with what we understand as critical to care and the conditions required to provide that care. Our research makes it clear that context matters and there is no one-size-fits-all model. But there are some critical conditions for care we can identify through comparison across countries. There is little doubt that minimum staffing levels are essential to ensure there are enough hands to support care relationships that build on strengths and attend to individual needs. To ensure the continuity and teamwork that is central to these relationships, it is necessary to have a majority of staff employed full time by the home, with flexibility provided by permanent part-time staff. To ensure that staff can respond to individual needs, they need the skills, the autonomy, the flexibility, and the time – as well as a leadership that supports and protects their work. To ensure staff is there, there needs to be appropriate equipment, continual training, pay and benefits, and a supportive, safe, physical environment. In addition, there need to be structures that allow all those who live in, work in, and visit care homes to participate in decision-making. Such conditions make it possible for residents to have some autonomy and choice about their lives and care. In doing so, it is critical to attend to equity and diversity (Um, 2021).

Years ago, we switched from asking what are you looking for in a care home for your mother, to asking what would you like in your care home? We all have a vested interest in making care homes as good as they can be.

**REFERENCES**


Care homes in a turbulent era


4. The crisis in the nursing home labour force: where is the political will?

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There is no care without care workers. When it comes to the nursing home labour force, the pandemic turned what was a dire situation into a crisis, with working conditions driving staff out of care. Well before Covid, international reports had been warning that population aging, combined with the poor working conditions in the sector, would mean severe shortages (e.g., Colombo et al., 2011). We also had warning that the increasing shift to for-profit services and to for-profit approaches to the organization of work, combined with “aging in place” policies, was limiting access to care while undermining the quality of work and the quality of care (Armstrong & Armstrong, 2020). As nursing home places failed to keep up with demand, entry into these homes was increasingly restricted to those with complex care needs. Covid turned barely enough care into not enough care as workers became ill or left because they feared getting ill, as part-time employees were restricted to one workplace, as schools closed so children were at home all day, as working conditions deteriorated, and as families were barred from care homes.

In this chapter, we begin by looking at the nursing home labour force in Canada, Norway, and Sweden pre-pandemic. Because Canada has a federal system that leaves responsibility for health care primarily to the provinces and territories, resulting in considerable variation across the country, we focus mainly on Ontario, the most populous province. We draw on our nearly two decades of research employing multiple methods to study nursing homes in six countries (Chapter 1). We then turn to strategies introduced during the pandemic to shore up the labour force, asking whether these strategies are temporary or permanent. Finally, we explore whether these policies address the long-standing issues in the conditions of work that have been identified as necessary to support this labour force.
WHO PROVIDES CARE?

All nursing homes need people to provide social support as well as clinical care, therapy, recreational activities, assistance with daily living, food, clean clothes and environments, maintenance, and management, although the balance among who provides these aspects varies across jurisdictions. However, comparisons across jurisdiction in the nursing home labour force are complicated by the differences in the titles of jobs, the division of labour, and in the kinds of formal and informal education required. Canada has a more detailed division of labour than either Norway or Sweden, with more specifically defined areas of work for each job class (Daly & Szebehely, 2012; Laxer et al., 2016). But even within Canada, there are different job titles and differences in the scope of practice for different occupational categories in different provinces and territories. Moreover, international data comparisons often lump together all long-term care rather than separating out the nursing homes primarily caring for older people, as we do in this book. Nevertheless, it is possible to identify some overall patterns.

The most comparable category is Registered Nurse (RN), with all three countries requiring a university education to qualify for this title. About 30 percent of the workforce in Norwegian nursing homes are RNs, compared to 7 percent in Sweden (OECD, 2020, p. 64) and 8 percent in Ontario (Ontario, 2020, p. 10). At the same time, Sweden has the largest proportion of the workforce that is assistant nurses; they account for almost 60 percent of the care workforce (Socialstyrelsen, 2021), a group roughly equivalent to Registered Practical Nurses (RPNs), who make up about 17 percent of the Ontario care labour force. But unlike the Swedish assistant nurses, RPNs are regulated (Simmons, Rodrigues, & Szebehely, 2021).

In Ontario, most care is provided by care aides who have limited formal training, while this is the case for only about a fifth of the workforce in Norway and Sweden. Meanwhile, physicians, therapists, and others with many years of formal training account for the smallest proportion of the nursing home labour force in Ontario (Marrocco, Coke, & Kitts, 2021, p. 15), and the training they receive is usually not focused on the nursing home population (McGregor, 2016).

In addition to those who provide direct care, there are those who cook, clean, and do laundry. Care aides or assistant nurses do some of this labour, especially in Norway and Sweden. But in all three countries, the heavier aspects are often done by those specifically assigned to this work, with little formal training. This is especially the case with those working for services that are outsourced to for-profit concerns, like the Canadian cleaner we interviewed whose company moved her from a job at the airport to the care home without...
providing her with any new training. In Canada, there are also a growing number of personal companions who are hired directly by relatives to make up for the gaps in care (Daly & Armstrong, 2016). There are no legal requirements for those doing this work, but individual homes may restrict their activities.

And there are virtually no requirements for the many relatives and volunteers who do unpaid work in care homes (Chapter 8). Like the paid labour force, most of these workers are women. In Canada, families and volunteers take on a much wider range of tasks than in Norway and Sweden, including tasks that are otherwise done by paid staff. But in all three countries these unpaid workers provide residents with essential social connections.

### Care for Women by Women

Care theorists have for years demonstrated that social inequalities related to race, gender, class, and citizenship status shape who does the paid and unpaid care work (Armstrong, 2019; Braedley, 2006; Duffy, 2011). Nursing homes are primarily about care for women by women. In all three countries, nine out of ten nursing and direct care staff are female, and a significant majority of residents are women. That so much of the work is done by those with limited formal training reflects and reinforces assumptions that care work comes “naturally” to women, and thus requires little formal training. That the care is for older women may also be a factor in the undervaluing of the care work, reflecting agism, especially in relation to women (Chrisler, Barney, & Palatino, 2016). Yet when asked about skills, a nurse said she used a much broader range of skills in the nursing home than she ever did in a hospital: “I think the stuff we have to do calls on so many aspects of nursing that would blow a hospital nurse’s mind. I really do” (Armstrong et al., 2019).

Working conditions and the valuing of this labour have made it increasingly difficult to recruit staff in these high-income countries, prompting a search for workers from outside their jurisdictions. In all three countries, a growing number of workers are immigrants and many of them are racialized. In 2020, 32 percent of the assistant nurses and 46 percent of the care aides in the Swedish care workforce were born outside Sweden, with male care workers almost twice as likely as their female counterparts to be foreign-born (Statistics Sweden, 2022). At 17 percent, Norway has a lower proportion of foreign-born care workers, but the numbers are growing (Statistics Norway, 2018). In both countries, the majority are from Asia or Africa (Statistics Sweden, 2022; Statistics Norway, 2018).

The proportion of newcomers and racialized people is even higher in Canada (Harun & Walton-Roberts, 2022; OECD, 2020, figure 2.6). Ontario data show that about 40 percent of care aides are racialized (Ontario, 2020, p. 5). And in both Canada and Sweden, around 60 percent of care workers in
The crisis in the nursing home labour force

urban areas are immigrants (Estabrooks et al., 2020, p. 19; Storm & Lowndes, 2021). These workers often face both discrimination and precarious working conditions (Storm & Lowndes, 2021).

The differences in the composition of the three countries’ labour forces are more in degree than in kind. Norway has significantly more RNs, which may mean more effective infection control, but may also mean a greater focus on medical rather than on social care. A 2016 Norwegian study (Kjøs & Havig, 2016) found that “the level of physical and social activities offered to the residents is relatively low, while the general care level is significantly higher.” In all three countries Covid highlighted the problem of too many staff with limited formal education and too many part-time workers. It also showed that Canada relies much more heavily than the other two countries on unpaid work by volunteers and relatives. All have a primarily female labour force which includes an increasing number of immigrant and/or racialized workers, factors that contribute to the working conditions and skill requirements in the sector, as we explore in the next section.

WORKING CONDITIONS

Staffing Levels

The most critical working condition is the number of staff. It is not surprising that all the models of care considered in Chapter 6 begin with high staffing levels. Low staffing levels mean heavier workloads for every worker. They also mean a greater focus on tasks, more tasks left undone, and lower quality of care overall (Armstrong et al., 2009; Harrington et al., 2012). Moreover, low staffing levels undermine workers’ health because not only are they working too hard and fast, but they have less time to support each other. In our survey of workers conducted more than a decade ago, 58 percent of the Canadian direct care workers said that all or most of the time they had too much to do, compared to 39 percent of the Norwegians and 40 percent of the Swedish respondents (Armstrong et al., 2009, table 7). If anything, things have deteriorated since then, with Covid making it even worse (Simmons et al., 2021).

The needs of the residents are quite similar in these countries. A critical difference, though, is staffing levels. Until Covid, Ontario required only one RN on staff and had no minimum staffing levels, while Norway and Sweden had no legislated staffing levels at all. It is hard to do exact comparisons because of the differences in the division of labour described above, because of the differences within countries in staffing levels, as well as in regulations, and because of the limited data available. Yet however the count is done, it is clear that staffing levels are much higher in Sweden and Norway than in Canada (Harrington et al., 2012; OECD, 2020). At the time of the survey,
staffing levels in Scandinavian care homes were estimated to be two to three times higher than in Canada (Harrington et al., 2012). And staffing levels do not usually count who is actually at work. While in our survey 46 percent of care home workers in Norway and 42 percent in Sweden worked under-staffed at least once a week, 46 percent of Ontario workers experienced working under-staffed on a more or less daily basis (Armstrong et al., 2009, p. 59).

Staffing levels are clearly higher in Scandinavia than in Canada. Current estimates for Sweden indicate that there are 3.3 residents per care worker on weekdays, daytime, and 4 residents per worker on weekends (Szebehely, 2020), while those for Norway indicate more than three times as many care workers and just under three times as many nurses as Canada (CIHI, 2020, table 2). Ontario residents average 2 hours and 45 minutes of care per day (Marrocco et al., 2021, p. 49), well below the minimum of 4.1 hours recommended more than a decade ago when care needs were less complex (Harrington et al., 2020). For-profit homes have even lower staffing levels, bringing down the average.

It is not only the number of staff that has an impact on the quality of work and the quality of care. It is also the proportion of work done by full-time, permanent employees. In all three countries, a significant number of workers are employed part time or on a casual basis, and this is especially the case for women. Part-time staff are less likely to know residents and the care home, making more work for full-time staff and making it harder for those working part time to support each other, undermining both continuity in care and teamwork. Part-time staff can also spread infections when they cobble together a living wage by working in multiple places. Just over half of the publicly employed eldercare workers in Sweden are employed part time, compared to 70 percent in the private sector. In Ontario, only two-fifths of the nursing and care aide staff are employed full time (Ontario, 2020, pp. 1, 5). Although arduous working conditions or private life circumstances push some to prefer part-time employment, many in all three countries want full-time work (Drange & Vabo, 2021). In Sweden’s private nursing home sector, this is the case for two out of five employed, compared to just under a quarter in the public sector (Municipal Workers’ Union, 2021), and for half the Ontario care aides and three-quarters of the nurses.

Casually employed and agency workers create similar issues for permanent staff and for care quality, but they are even less likely to know the residents, other staff and the nursing home systems. Increasing numbers of workers in all three countries are employed temporarily by the day or even by the hour (OECD, 2020, figure 4.10). Among publicly employed Swedish care workers, one in four are employed by the hour. In Norway, more of these workers are on permanent contracts but are employed for fewer hours than they want
The crisis in the nursing home labour force

(SALAR, 2022; Drange & Vabø, 2021) while one in ten Ontario personal support workers are casual (Ontario, 2020, p. 5).

Data on staffing numbers are much more difficult to find for those who do the other work in long-term care, especially if their work is outsourced to other employers. Those in professional categories other than nursing often work part time, such as doctors and therapists, and this may well be the case with those who cook, clean, and do laundry. This was certainly the case in many of the homes we studied and is more likely the case when the work is outsourced to private companies. There is little detailed data on the hours worked by relatives, volunteers, and private companions either. As Chapter 8 shows, this unpaid labour can enhance or undermine the working conditions for paid staff.

In sum, staffing is a critical working condition. Staffing is significantly better in Norway and Sweden than in Canada and is evident in their higher retention and recruitment rates (OECD, 2020, figure 4.3), but Covid revealed weaknesses in all three countries. The Ontario Long-Term Care Commission heard evidence on a correlation between the increased severity of a Covid outbreak and greater mortality with both a lack of staff (especially care aides) and the use of agency staff (Marrocco et al., 2021, p. 21). Similarly, the Swedish Corona Commission pointed at the high levels of casual employment as a risk factor during the pandemic and concluded that “the employers must improve employment security and staff continuity in elderly care and sharply reduce the proportion of staff on zero-hours contracts” (SOU, 2020, p. 5). The parallel Norwegian investigation identified issues related to integrating these workers, and highlighted problems with cleaning and maintenance staff tending to work part time and for a private company (Jacobsen et al., 2021).

Workers’ Health Risks

Nursing home work can be dangerous, and low staffing levels increase the risk. In our survey, Canadians were more than five times as likely as their Nordic counterparts to say they faced violence on a more or less daily basis (Armstrong et al., 2009, figure 28). Unwanted sexual attention was also much more common in Canada. Before Covid, the health sector ranked second highest in terms of time lost from injuries and “long-term care workers are among the most at risk for physical injury within the sector” (Ontario, 2020, p. 15). The most common injuries that result in work absences are musculo-skeletal disorders, exposure to chemicals or contaminants, slips, trips, falls, and violence.

In both Sweden and Norway accidents are more likely to occur in nursing homes than in hospitals (OECD, 2020, figure 4.12), with Sweden reporting numbers just above OECD averages and Norway just below. Pre-pandemic, Norwegian work absences due to illness or injury were higher than in other
sectors (Grødem, 2018), and in Sweden, assistant nurses in eldercare have the
highest absences of all occupations (Swedish Social Insurance Agency, 2022).
But documented work absences hide the daily dangers workers face, especially
from frustrated residents who lash out when staff do not respond quickly,
or have no time to do tasks slowly, or to chat. Staff showed us teeth bites,
scratches and bruises, and other injuries that did not get reported. Instead, as
one Canadian care aid explained,

[W]e’re told “Suck it up. It’s your job.” And that’s so frustrating because that’s not
my job. It’s not my job to come to work and expect to be punched in the face. You
know, it’s not my job to come to work and expect to be hurt because you didn’t staff
the building properly so now I can’t take care of my own family. (Braedley et al.,
2017, p. 91)

In our survey, 43 percent of Canadian workers said they almost always fin-
ished the day mentally exhausted, but this was the case for only 8 percent of the
Norwegian respondents and 16 percent of the Swedish ones (Armstrong et al.,
2009, figure 23). Canadian direct care workers were more than twice as likely
as their Norwegian counterparts to say they almost always ended their shift
feeling inadequate (Armstrong et al., 2009, figure 19), and they were almost
three times as likely as their Swedish counterparts to say that work keeps
them awake at night (Armstrong et al., 2009, table 20). But workers in all
countries felt the strain, and current research shows increasing strain (Stranz
& Szebehely, 2018). In Ontario, half of care aides leave within five years and
43 percent of them leave because of burnout related to staffing (Ontario, 2020,
p. 6).

Racialized staff may face additional health issues. They are more likely to be
employed part time and work in multiple workplaces, experiencing precarious
conditions that in themselves put them at risk. Indeed, such precarity may
be a form of indirect racism that is more common than direct comments and
exclusion (Simmons et al., 2021), although racist comments from residents,
families, and other staff are common too and our research indicates that men
in Sweden and Canada often face both direct sexism and racism (Storm,

Limited training to meet current needs also poses a health risk (Simmons
et al., 2021, p. 8). The increasingly complex needs of residents require formal
preparation not only on entering work in nursing homes but on an ongoing
basis. Those coming from another country also need education in the dominant
culture and language to feel comfortable, and all staff need training in the resi-
dents’ different cultures as well as in gender issues to help them avoid stressful
interactions.
Pay and Benefits

Pay and benefits determine workers’ access to essentials for living but they also indicate the value attached to them and their work. When we interviewed a human resources director in a Norwegian nursing home, we asked what had surprised her in her move from a corporate workplace. “How hard these women work!” she replied. Asked what she would do if she were in charge, she said, “I would pay these women what they pay the men on oil rigs, because the women work harder.”

The relatively high rates of unionization in the sector provide some protections for permanent staff in all three countries, but this protection usually excludes those in casual or outsourced jobs. In Canada collective bargaining is often done for each facility and each union within facilities, so it is common for nursing home staff to be paid less than their hospital counterparts and for wages to be relatively low, especially compared to male-dominated unionized sectors. And wages are lowest in for-profit homes (Marrocco et al., 2021). Centralized bargaining helps explain why Sweden pays amongst the highest wages for this sector in the OECD (OECD, 2020, figure 4.5), as does Norway. And Sweden and Norway pay the same rates in hospitals and nursing homes.

Collective bargaining usually provides permanent staff with benefits such as pensions and sick leave. In Canada, paid sick leave is up to the employer or the collective agreement, with unions ensuring permanent unionized staff have some paid sick leave. However, sick leave coverage for part-time workers is limited and it usually does not exist for casual employees. Indeed, saving this cost can provide an incentive to employers to move away from offering full-time work. In Sweden, employers pay sickness benefits but the first day of illness is not paid. The one-day gap can be critical in health care, where workers going in sick put everyone at risk. Moreover, in Sweden, the growing number of casual employees who work in multiple workplaces are paid sick leave only for the days they are scheduled.

All three countries have universal medical and pension plans. Nevertheless, in Canada the kinds of extra benefits that unions negotiate are often denied to non-permanent employees and the growing number of immigrants working in health care can have only limited access to the universal benefits, while the low pay in the sector makes it difficult for them to pay privately. Unions can also provide workers with more power on a daily basis, allowing them the right to say no to unfair requests or conditions, while casual employment limits this power.
Work Organization

The more detailed division of labour in Canada than in the Nordic countries reflects both workers’ efforts to protect their areas of work and the regulatory bodies that define scope of practice. These efforts have been shaped by regulatory rigidities (Baines & Daly, 2015) that have frequently been introduced in response to scandals, especially in for-profit homes (Lloyd et al., 2014). In North America, this has primarily meant more regulation of workers and more detailed documentation required of them, increasing surveillance over workers and reducing the time available for care without addressing larger structural issues (Chapter 10).

Nordic countries tend to have a more interpretive approach to regulation, identifying what to do but not when and how to do it, compared with the more prescriptive regulation in Canada that tends to identify what to do as well as when and how to do it (Daly et al., 2016). The Nordic approach may provide workers with more autonomy in applying their skills, although we saw considerable variation in the autonomy experienced by assistive personnel within the three countries (Jacobsen et al., 2017).

The flexible division of labour more common in the Nordic countries promotes the teamwork that allows staff to support and learn, both with and from each other in teams, especially when there is effective leadership and ongoing training (Choiniere, 2017). As one nurse we interviewed put it, “Teamwork is important because when you pull together, you get the best outcome and when you also work as part of a team, you know it makes life more joyous in a nursing home” (Armstrong et al., 2019). However, we also saw teamwork and flexibility undermined by outsourcing, which means staff have multiple different employers and there is more part-time, agency, and casual work and low staffing levels.

Workers in all three countries raised issues about scheduling. The workers we interviewed want more input into scheduling and more flexibility in hours to allow them to have a life outside their work. Some take scheduling into their own hands, trading shifts with other workers. Leadership is important here, as it is in the overall organization. Leaders who work with staff and include them in decision-making can improve both the quality of work and the quality of care. Indeed, involving the entire range of staff, families, and residents in decision-making can improve overall conditions, as they are experts on what is needed.

Workspaces

Physical environments shape both work and health. Factors such as clean air, the limited use of call bells, safe, easy-to-use equipment, flooring that makes
it comfortable to move wheelchairs, toilets placed to fit walkers, and effective lighting are just as important for those who do the work as they are to the residents (Chapter 7). Staff have shown us lifts over beds that cause them to strain their backs, medicine cabinets too high for them to reach, corridors with poor sightlines, and linen bags weighing too much to carry comfortably. These are only some of the features that make their work harder or even dangerous (Armstrong & Braedley, 2016). Larger structural features, such as the location of the nursing home, which determines access for both families and staff, and pleasant, separate spaces for staff to take breaks and to grieve, rather than in dark basements or crowded rooms in public view, are also critical to the conditions of work (Chapter 7). Tapping the expertise of those who work and live in the care home can go a long way towards designing workspaces that work for everyone.

In sum, working conditions are driving workers out of care. When our research began two decades ago, the Nordic countries clearly had significantly better working conditions than Canada. While this is still the case, none of the three countries has sufficiently adjusted staffing and training to meet the increasingly complex needs of residents, and increasingly they have all expected relatives to provide some unpaid care (Rostgaard et al., 2022). Recent Swedish research indicates worsening health and stress issues, along with growing numbers of workers wanting to leave the sector (Simmons et al., 2021; Stranz & Szebehely, 2018). Funding, ownership, regulations, and for-profit approaches to work provide the context. In Canada, for-profit homes “tend to offer lower wages and benefits to their staff, have higher staff turnover, and have lower staffing levels and staff-skill mix” (Marrocco et al., 2021, p. 68). Following Farmer (1996), we argue that these conditions are a form of structural violence that prevents nursing home workers from reaching their potential (Banerjee et al., 2012). Covid has made many of these conditions worse, while adding new ones.

RESPONDING TO COVID

Covid hit nursing homes hard. In Canada, this was especially the case in for-profit homes (Stall et al., 2020). All three countries stepped in and then stepped back in addressing the labour force crisis that was clearly a factor in protecting nursing homes. They initially focused their attention on hospitals, but the rising death rates and a shortage of both workers and Personal Protective Equipment (PPE) rapidly brought attention to nursing homes. All three countries initially banned relatives, until it became obvious that relatives provided social support, often along with other essential care, especially in Canada, where relatives undertook a broad range of tasks (Chapter 8). Many doctors began to work remotely while those providing care faced increasing
stress and issues with communications from governments. Although the countries responded in different ways that reflected their conditions, they all set up special commissions to investigate the crisis and made the labour force a primary concern. The Norwegian commission alone did case studies of nursing homes. But few major reforms have followed, in any of the countries.

Across all three countries, labour shortages resulted from the increasing pressures on staff that reflected both past and current conditions, and from work absences due to Covid and burnout. Workers stayed home because they too were ill or simply could not take it anymore, because they needed to provide care to a family member, or for children when schools closed in Norway and Ontario, or because they feared contracting the disease. The response varied, however.

Ontario suspended inspections and restricted workers (other than those from agencies) to one workplace, without offering any special supports (Carter, 2020). The federal government poured in money for PPE, provided vaccines that Ontario mandated for all health care workers, and sent in the military to rescue four Ontario care homes, all non-government owned. Pre-pandemic, the Ontario government limited wage increases for most health care workers to 1 percent for three years, legislation that further exacerbated the low pay in the sector. Responding to Covid, the government initially provided a temporary three-dollar raise to care aides, a raise made permanent in 2022. Nurses were offered one-time bonuses of $5,000 available to some, but no other wage increases. “A Plan to Stay Open” (Ontario, 2022) included a tuition refund for some nurses working in underserved areas, training for more doctors, and strategies to recruit more foreign trained workers.

Ontario did virtually nothing about working conditions, except for offering temporary, short-term, paid sick leave. The plan to train 6,000 new care aides did not learn from the province of Quebec, which hired and trained nearly 10,000 care aides during the pandemic, only to see 10 percent of them quit within the year because of working conditions (Radio Canada, 2022). In direct contradiction to the stress on the need for more training, Ontario introduced a “resident assistant” category – workers with no formal training or clear job description. Meanwhile, the government is funding new beds, many of which are in for-profit homes where working conditions tend to be even worse than in other care homes. Responding to the Commission, Ontario announced a target of four hours of care per resident per day – a minimum higher than current levels but far below current needs (Chapter 3), and with few penalties for failing to either report or meet these levels. There was limited progress on cleaning the care homes’ air and the call for all residents to have private rooms was largely ignored.

During the pandemic, the Swedish government provided increased funding for staffing and for training 10,000 temporarily employed care aides to become
permanently employed assistant nurses. It also temporarily introduced pay for the first day of sick leave. Although the Corona Commission concluded that staff security and care continuity must be improved, it is not clear what is being done (SOU, 2020, p. 5). Following the Commission call for minimum training requirements, the government introduced legislation on a national standard for assistant nurses. In summing up, the Commission’s interim report pointed to the “structural shortcomings that have been well-known for a long time … Staff employed in the eldercare sector were largely left by themselves to tackle the crisis” (SOU, 2020, p. 2).

In Norway, decision-makers became increasingly aware of the need for adapting to and caring for residents’ families, leading to greater accommodation supporting their participation. However, there has been no parallel increase in awareness of the need for strengthening the support for staff. Although working conditions were highlighted by the pandemic and in reports, there were few permanent or significant improvements in working conditions other than in infection control. Meanwhile, some tasks usually restricted to nurses were temporarily assigned to other staff who did not have the training. Although some issues were raised about temporary and part-time workers, such as cleaners and food service workers, it is not clear what this means in the long term. With responsibility for care homes primarily left to municipalities, concern was raised over national leadership and problems with communications around strategies to address the pandemic. At the same time, however, Norway reported that the pandemic supported more cooperation and cohesion among some staff and increased knowledge of infection control.

All three countries introduced some measures to protect residents and staff, but many measures were temporary, like sick leave and bonuses. Problems with casual and part-time employment were acknowledged. However, little was done to address this issue in the long term. The need for skills was recognized at the same time as those without formal training were required to do the work. Norway, with higher staffing levels and more RNs, did better than either Canada or Sweden (Comas-Herrera et al., 2022).

SUPPORTIVE WORKING CONDITIONS WOULD TRANSFORM NURSING HOMES

The pandemic has made it clear that the conditions of work are the conditions of care, that poor conditions are driving workers out of care and that without a workforce, there is no care. Planning begins with recognizing that nursing homes are places of work and places to live as well as places to receive skilled care and support. It also means recognizing that care is a relationship. A nurse we interviewed explained that the “relationship that you build with them … helps you to care for them because you get to know them on a different level
and you get to know exactly what their needs are and how to approach them when it comes to certain things” (Armstrong et al., 2019). Looking after residents and creating relationships requires looking after staff.

As the Swedish Corona Commission (2021, p. 15) put it, it is necessary “to offer health care staff working conditions that encourage them to remain and develop in their professions.” Years of research, years of reports, and years of commissions have identified essential ingredients in those conditions. They begin with an appropriate number of staff, with the appropriate skills (Harrington et al., 2020). Norway was able to limit Covid’s impact in part because of the large numbers of RNs on staff. Determining staffing numbers means taking the increasing complexity of resident needs into account, while also understanding the critical importance of social supports for residents, staff, and families. Determining the skills required means recognizing that specialized skills are involved in the entire range of care work – whether it is cleaning or clinical, whether it is done by staff, families, or volunteers. Skills training should be provided as part of the job as the resident population grows and the research develops. These skills include learning about what is called cultural safety (Curtis et al., 2019), understanding the power imbalances related to race, gender, sexuality, and culture for residents, staff, and families.

And staff skills, as well as the demanding and responsible nature of the work, should be recognized in pay, benefits, and work environments. Access to fully paid sick days is important for all the staff, given that they are in contact with people in fragile health every day. Physical and social environments and equipment need to be designed for both safe work and safe living, while recognizing a healthy life involves some risk. At the same time, given the health risks of the jobs, a wide range of injuries and illnesses should be automatically recognized as work-related and deserving of compensation.

To develop care relationships with residents, families and other workers, staff need security. This means permanent employment, whether the employment is full time, which should be the case for the majority, or part time, to allow flexibility. Employment security allows teams to develop, especially when combined with appropriate training for staff, considerable autonomy in applying those skills, and leadership that promotes all of the above. Security and teamwork in turn require that all those working in the home have the same employer, avoiding any outsourcing of services. Unions are important in supporting security in multiple ways.

Care relationships not only take time to build through the continuity that comes with permanent staff employment but take time during the workday and worknight. This means flexibility in the way tasks are carried out and a recognition that care involves much more than a set of tasks (Chapter 3). Care relationships outside the care home also need to be recognized and negotiated in organizing scheduling.
Means for effective communication and meaningful participation of all those who live in, work in, and visit care homes is a critical component in the structures that support working conditions. The pandemic emphasized the need for better means of communicating, better training in communicating, and better content in communications. Effective communications can provide the basis for effective participation in decision-making, which is another critical working condition that requires leadership and structural supports.

All these conditions depend on appropriate funding, regulation, and approaches to care, which our research indicates means avoiding for-profit ownership and methods (Armstrong & Armstrong, 2020). The pandemic has revealed major structural weaknesses in care homes, encouraging many to call for their abolition. Care homes could be transformed to offer a positive living and working space, and the experience of Covid offers the opportunity to learn how to make them as good as they can be. As one nurse explained to us, the work can bring joy:

It’s about making a real difference in my residents’ lives. If they are hurting, I can help ease that suffering for the most part. I can make them warm. I can get them something to eat. I can help them find something that’s lost. I can help them with social activities. Those little things are all about quality of life. (Armstrong et al., 2019)

The joy requires supportive working conditions. We know what to do, but it requires political will.

REFERENCES


5. Negotiating internal and external boundaries of nursing homes during Covid-19: a case study from Norway

Gudmund Ågotnes and Frode F. Jacobsen

What happened was that they [the residents] could not receive visitors. For those who usually didn’t get visitors, it wasn’t a big deal. But it was significant especially for two residents, who were very close to their families. They had a lot of visitors. Almost every day. And now, all of a sudden, it’s closed and they can’t visit. And one of them didn’t get it: why is it like this? It was difficult to explain. We saw that their general condition deteriorated, physically and mentally. One of them became bedridden, one wouldn’t eat and was very down. At that point we had to put in measures so that families could visit. Then we experienced that the bedridden resident came out of their bed and the other resident’s mood became better. (Registered nurse, nursing home, Norway)

This is not a voluntary work [dugnad], it is our job! (Focus-group interview of nursing staff, nursing home, Norway)

Covid-19 has severely affected the physical and mental well-being of older adults, and nursing home (NH) residents most of all (Comas-Herrera et al., 2020). Declines in physical and mental health (Levere, Rowan, & Wysocki, 2021), increases in the use of medication (Campitelli et al., 2021), more social isolation (van Maurik et al., 2020), as well as increases in the number of deaths (Thompson et al., 2020) have accompanied Covid-19 in nursing homes. Recent research also indicates why Covid-19 was more severe in some NHs or in some jurisdictions, highlighting the specific characteristics of different facilities that influenced the degree of contagion. In particular, research finds NH size (larger NHs, more contagion), ownership (for-profit status, more contagion), degree of urbanization (larger communities, more contagion), singular/plural occupancies (plural occupancies, more contagion), stability of staff (less stable, more contagion), staff coverage (less staff, more contagion), NH age (older NHs, more contagion), and designated staff areas (“open spaces,” more contagion), have all influenced the degree of contagion in NHs (Sabatino & Harrington, 2021; Ibrahim et al., 2021; Abrams et al., 2020; Stall et al., 2020; Anderson et al., 2020).
In this chapter we explore long-term care during the Covid-19 pandemic through the optics of “boundaries,” that is, the physical and imagined barriers inside and outside NHs. Our point of departure is the importance of boundaries to residents, families, and staff (Jacobsen & Ågotnes, 2023), recognizing that the boundaries within NHs have been particularly significant during the pandemic.

NHs are medically oriented facilities, treating and caring for a frail population, but they are also a last home for most residents. Like any home, a NH is closely connected to its physical surroundings. “Feeling at home” implies a connectedness to one’s neighbourhood. NHs are spaces interfacing with their surroundings, whether it’s a city centre, a suburban neighbourhood or a village, often serving as a base or a meeting place as well as a significant local employer for the immediate community. In addition to the traditional “key players” of medically trained staff and residents, other people play important roles: most notably, auxiliary staff of various kinds, volunteers, and residents’ significant others. These, especially volunteers and significant others, bring the outside into the NHs. In doing so they bring not only life and variation to an otherwise mundane “total institution,” but a form of transparency. Visitors have a “normalizing” effect on NHs (Jacobsen & Ågotnes, 2023) in at least two senses: they bring everyday life into NHs, and they serve as a control function by being a bridge between the seemingly self-sufficient institution and “ordinary life.”

Our focus is Norway, but the team’s research shows that the overall themes and dilemmas are of international and cross-jurisdictional relevance. In this chapter, we ask:

- How were boundaries inside the NHs maintained during the Covid-19 pandemic?
- How were the boundaries between the institutions and the outside community maintained?
- Did the boundaries change during the pandemic?
- What significance did the “boundary-work” have for residents, staff, volunteers, and family members?

We base our analysis on data collected for research commissioned by the Norwegian Corona Commission. Case studies were conducted in five Norwegian NHs, representing different geographical regions and having varying exposure to Covid-19, during the second wave. Thus, our investigation covers the “introduction” of Covid-19 to NHs. Individual and focus-group interviews were conducted with NH management, physicians, registered nurses, and auxiliary nurses, as well as with family members of residents of the included NHs. The study also included analysis of statistical data on
Internal and external boundaries of nursing homes during covid-19 reported infection and deaths attributed to Covid-19 during the first year of the pandemic, as well as document analysis (as provided by the included NHs and municipalities) and floor plans of the NH buildings (Jacobsen et al., 2021). In this chapter we primarily draw on the qualitative data set, in an attempt to capture the voices and experiences of those living in, working in, and moving within and between the institutions during the Covid-19 pandemic.

Building on this data, we explore how residents, staff, family members, and volunteers were able to enter NHs and access different wards during the pandemic. Our aim is not only to understand preparedness and practices for the ongoing and future pandemic(s), but to understand the more general function, relevance, and significance of NHs in present-day society, in keeping with the overall topic of this book.

LONG-TERM CARE IN NORWAY

Norway, like the other Nordic countries, has frequently been described as a generous welfare state (Rostgaard et al., 2022). Long-term care in the form of NHs has been the dominant mode of public care provision for the older adult population, historically and in recent times. In stark contrast to the other Nordic countries (Rostgaard et al., 2022), the number of NH beds has hardly declined in terms of absolute numbers of beds. This tendency perhaps indicates a stronger and more stable economy, and a welfare state less inclined to de-prioritize costly, institutional care in times of austerity. The coverage relative to number of older adults has, however, declined in Norway (Statistics Norway, 2021), reflecting the growth in the older population. NHs remain an important institution in Norway, as a workplace, as a community centre in rural areas, and, not least, as a last home for the oldest and frailest. As a workplace, Norwegian NHs are characterized by relatively high staffing levels as well as by high levels of formally trained staff, especially registered nurses and licensed vocational nurses (Harrington et al., 2012). Traditionally, the NH workforce has been dominated by native-born women, but increasingly they are being replaced or supplemented by migrant workers and immigrants, including a higher proportion of men (Ågotnes & Storm, 2022). A recurring challenge for the NHs’ workforce, and especially for those in less prestigious positions (without, or with a low degree of, formal training), is a high prevalence of part-time positions (Jacobsen et al., 2018).

Despite a decline in the relative number of NH beds, around 45 percent of persons over 60 years of age die in NHs in Norway (Statistics Norway, 2020). Most NHs in Norway are not only publicly funded but publicly operated, having comparatively small yet historically significant private, non-profit contributions, and low and more recent for-profit providers (Ågotnes, Jacobsen, & Szebehely, 2019), the latter steadily declining since 2015 in terms of share...
Care homes in a turbulent era

of total NH beds (Statistics Norway, 2021). The prioritization of long-term care in Norway is evident not only in the number of total beds, but also in overall spending in the sector when compared to other countries (Szébehely & Meagher, 2017). Most NHs are also fully occupied and have long waiting lists (Norwegian Directorate of Health, 2022).

Aging at home is also promoted in Norway, with a shift towards the prioritization of home help care, supportive housing, rehabilitation, and prevention (Rostgaard et al., 2022). Another noteworthy development, following reforms in recent decades and especially the so-called “coordination reform” in 2012, is a shift towards greater local/municipal responsibility of care for the older adult population. Municipalities have considerable autonomy in how to prioritize the “welfare mix” – between home help care, assisted living, other services, volunteer efforts, and informal care (Ågotnes, Moholt, & Blix, 2021) – leading to discretionary differences among municipalities (Førland et al., 2020). Even so, considerable uniformity characterizes Norwegian NHs, not least regarding staffing levels (Graverholt et al., 2013), especially compared to other counties (Harrington et al., 2012).

Public investment in NHs can be described as comparatively high in Norway, including investments in publicly owned NH buildings (Jacobsen, 2021). Since 2000, investments in the renovation of NHs have been particularly high, following two white papers stating the need for smaller wards and single occupancies with separate bathrooms (Ministry of Health and Social Affairs, 1996–1997; Ministry of Social Affairs, 2001–2002). Today, over 90 percent of NH rooms are single occupancies with separate bathrooms (Statistics Norway, 2021), while most wards are comparatively small, with around ten residents.

Norwegian NHs, then, are both historically and currently significant, and are an example of continued public care, despite recent development to the contrary. Even compared to other Nordic countries (Rostgaard et al., 2022), NHs in Norway are very much alive and kicking, or at least they were until the spring of 2020.

THE COVID-19 PANDEMIC IN NORWAY

After several days of intense debate between the government and various public agencies, on March 11, 2020 – the same day the WHO declared Covid-19 to be a pandemic – the Norwegian Health Secretary called for a widespread and nationwide effort to combat Covid. Only one day later, a lockdown was implemented. Different age groups or categories were not mentioned explicitly, although, for instance, the government warned that grandparents should not take on responsibilities for grandchildren. The overarching strategy of the Norwegian government was, in contrast to Sweden, to limit contagion as much as possible and over time – primarily through two
Internal and external boundaries of nursing homes during covid-19

major lockdowns – in anticipation of a forthcoming vaccine. According to the Norwegian Corona Commission, this overall approach has been reasonably successful, both regarding the prevention of deaths and the overall economic cost of measures implemented. Although deaths attributed to the Covid-19 pandemic are comparatively low in Norway, older adults, as elsewhere, are overrepresented.

Throughout the ongoing Covid-19 pandemic, the protective measures in Norway altered between periodic societal lockdowns and more general appeals to all citizens to be cognizant of interactions in public and private spaces, emphasizing “the old and frail” in particular. As in other countries, measures of self-isolation, hygiene, and social distancing were encouraged or imposed, to varying degrees at different periods of time. As an overall strategy, the Norwegian government sought to reduce the pressure on the specialized health care sector, and acute wards in particular, throughout the pandemic. Consequently, the national Health Directory (Jacobsen et al., 2021) explicitly stated that residents in NHs should, if possible, be treated in NHs. This strategy implied, as elsewhere, strict protective measures for NH staff and residents, in which the movement of both staff and visitors were greatly limited. The boundary control was severe, both externally and internally, in times of “the most intrusive measures taken in peacetime in Norway,” as stated by the prime minister.

BOUNDARY WORK IN NHS DURING THE PANDEMIC

During the first year of the pandemic, around 50 percent of all deaths in Norway attributed to Covid-19 occurred in NHs (Jacobsen et al., 2021). Approximately 3 percent of the total NH population was infected by Covid-19 and around 1 percent of the total NH population died from it. While this is indeed high, the most interesting finding from our data was the considerable variation among NHs. Of the total number of reported Covid-19 cases in NHs, around 40 percent occurred in only ten (of a total of 800) NH institutions. The “clustering” of contagion is confirmed elsewhere, showing that almost every fifth death during the first months of the pandemic occurred in only three NHs (Strand, 2020). In other words, only a relatively small number of NHs was affected by Covid-19, and those that were affected had relatively large outbreaks and a high number of deaths.

From our qualitative data, physical barriers and buildings were highlighted as (a) important for stopping outbreaks of Covid-19, and (b) containing further spread when an outbreak occurred. We discuss how this was handled during the first wave of Covid-19 outbreaks in NHs by addressing how boundaries inside and outside NHs were created, protected, and changed.
Internal Boundaries and Boundary Work

In addition to not having enough protective gear and inadequate staffing, the NHs most severely hit by Covid were those housed in old and impractical buildings (Strand, 2020). The architectural features of NHs were also highlighted by our informants as important in the everyday struggles to limit or prevent contagion. This included both physical areas for residents (residents’ rooms, shared spaces, and air locks between the various spaces) and areas for staff (wardrobes, break rooms, and rooms allocated to receiving goods from the outside).

The most important feature of the built environment, as reported by NH staff, was how wards were connected (or not) and how access to wards was arranged. At one NH, for example, the wards were spread out over four floors with very narrow hallways. This meant that movement within the NH was difficult, especially for bedridden residents. Moreover, various NH equipment was stored in rooms serving the entire NH, making transportation an everyday and ongoing struggle, made more problematic during the pandemic when demands for hygienic products rose considerably. Because of these physical conditions, staff also had to work between floors and wards, increasing “traffic” in the NH.

At a second NH, similar challenges surfaced at the start of the pandemic, despite the home being newly built and considered “state-of-the-art.” The NH experienced contagion in one ward, and quickly had to adapt to a new reality. As reported by the NH staff, spaces were adapted or altered either through new permanent solutions or more ad hoc features. The hallways were “cleaned” of everything not considered vital and shelves containing hygienic articles were put up. The medicine room was transformed into an equipment room for cleaning and hygiene materials. However, this was not considered an ideal solution because the utility room was placed far from the infected ward. To use the equipment room, staff had to move from the ward and through the “safe” part of the NH. Similarly, waste disposal was also located at the far end of the NH, meaning that staff had to bring contaminated goods through the safe areas. Staff members at this NH also lamented the inadequate private staff areas at the NH, making changing in and out of work clothes a constant struggle. All staff, whether they worked on infected or non-infected wards, used the same wardrobe. Despite these challenges, contagion was limited to the one ward.

At another NH, the physical conditions were described as even more precarious – as poor to begin with and as especially problematic when pandemic restrictions started. Two aspects were highlighted, one more fundamental and related to the architectural layout and one seemingly mundane yet important in efforts to prevent contagion. First, the NH did not have separate bathrooms for all residents as the national norms suggest. Twenty residents had to share
two large shower rooms, making it impossible to contain a potential outbreak, according to the nursing staff. Second, the worn-down surfaces at the NH were difficult to keep clean, despite wholehearted attempts by staff, and they were constantly unsure how safe their surroundings were. Moreover, staff noted the absence of “spaces in between” in the form of air locks, pointing to the need for a physical buffer zone between safe/clean and unsafe/dirty. In general, the nursing staff explained how well-intended rules, regulations, and routines were difficult to fulfill in practice. A nurse talks about a resident in isolation waiting for her test result:

You have the clean equipment in the hallway, and the dirty in the bathroom. If there is a bathroom, that is. And if there is no bathroom, then it’s much worse, because then you don’t have a buffer to the shared hallway even. And I think we should consider this before it can happen again. We should have a sort of barrier, a wall, small containers we can put things in and that can be quickly covered, you know, something … Because we can’t do it when it is like this. We have the equipment, but the physical conditions are not suited for infection treatment at all.

In contrast, at another, far older NH the physical conditions were experienced as less problematic. When one ward had infection, according to the manager, they contained it in the ward due to the physical structure of the NH. Being able to physically isolate wards from each other was particularly highlighted. The attending physician also emphasized how they managed to “isolate in cohorts,” pointing to the benefit of separate bathrooms for all residents and the relatively small wards. Each ward had its own living room and kitchen, meaning that wards with infection were self-contained to a large degree. Nursing staff also pointed to another promising practice: they changed one of the resident rooms to a staff room, making it possible for staff to have shorter breaks within the wards, as opposed to going outside a potentially infected space. All interviewees, the manager, ward leader, and nursing staff, pointed to one significant flaw, however: the absence of air locks going in and out of residents’ rooms.

In sum, staff and family members pointed to features of the interior built environment as important in combatting Covid-19 from entering NHs or in limiting its spread when the infection entered. Boundary maintenance or boundary work was addressed as particularly important and as something that constantly had to be adjusted and amended, based on the varying physical conditions in the NHs. These conditions, singular/plural occupancies, smaller/larger wards, and having transition rooms between safe and unsafe spaces meant that NHs to varying degrees were able to find what they considered to be adequate solutions.

Finding adequate solutions implied controlling the flow of people and objects within the facility. While this naturally implied an extra workload...
for NH staff, the consequences of maintaining boundaries were grave for residents. Although it was possible to isolate single wards, visiting friends in neighbouring wards was unworkable. When isolating single wards was impossible due to building structures, residents with infections experienced even more restrictions on their movements, and were subjected to isolation in their own rooms. In all cases, control of the entry of visitors, including the closest family members, reduced the quality of life for NH residents.

**Boundaries to the Outside World**

Boundary maintenance was not only important inside the NHs. The walls separating the institution from the outside world were also heavily guarded. The pandemic greatly affected how the institutions communicated and interacted with the world/communities outside their walls. As one NH manager expressed it, closing the NH to the outside world had never been done before, and was the aspect of the pandemic they were least prepared for. How this interaction was handled was to a large degree dependent on the physical location of the home (see also Jacobsen & Ágotnes, 2023).

Some interactions with communities outside the NHs continued successfully. For example, during the early stages of the pandemic, one small NH experienced a shortage of necessary infection equipment, as did many others. This was quickly solved when a local dairy farm provided the home with head visors used for milking cows. How interaction with the world outside carried on was also dependent on the choices, solutions, and adaptations NHs made when the pandemic hit.

Our research indicates four main areas of “boundary work” that were particularly important and challenging during the first phases of the pandemic: (1) the handling of transportation of residents and goods in and out; (2) communication with the outside world in new digital ways; (3) interaction with families and visitors; and (4) the mobility of staff members in and out. All these aspects also influence boundary work inside NHs.

One nurse described how the staff found new ways to bring residents in and out of the NH when, at the beginning of the pandemic, residents had to be transported to the hospital for testing (despite the national guidelines that stated they should be treated in their NHs). Deviating from the standard procedure of transporting residents through the main entrance, a back door was used, limiting contact with the presumed “clean” areas of the NH. This was not without problems, as a registered nurse noted: bedridden residents had to be carried up or down a staircase to or from the ambulance, as the back door was not connected to a ramp/elevator. Similarly, another NH created a new entrance that went straight into the contagion ward from an emergency exit door. This new point of entry remained locked at all times, and all exits and
entries were registered. Also, as noted by an NH manager, when residents died new procedures had to be made “on the spot,” especially at the initial and uncertain stage of the pandemic, due to uncertainties about if and how to use funeral agencies.

All the NHs explained how they began to rely on digital communication with “outsiders” after the first lockdown. This represented a steep learning curve for most. It entailed providing communication platforms between residents and families, as well as with colleagues and off-site management and other health agencies. At several NHs, this meant new and more extensive contact with municipal agencies and departments through teams or other digital solutions. This communication was described as necessary in “uncertain times,” especially at the beginning of the pandemic, and as a practice to be continued post-pandemic. The new collaboration with municipal offices, and especially the head physician, was described as an untapped resource that was made evident due to the pandemic. Others noted how digital solutions were used to enhance collaboration among staff, between those on shift, management, staff in isolation, and physicians. At several NHs various e-courses – such as courses on infection control – provided by municipal or federal resources were set up for all staff members.

Perhaps more significantly, the boundaries to the NH were strictly maintained for family members and volunteers, in various forms, depending on the ebb and flow of the severity of national contagion. This led to far fewer visits and social activities for residents during Covid-19, at considerable costs for residents. As a husband explained: “I have lost my wife three times; first when she became ill and got her diagnosis … then when the illness developed and I experienced the decline, and then when the coronavirus prevented us from meeting. She is there, but we don’t know when we will see each other again.”

Limiting access to NHs for family members and volunteers had important consequences for most residents, regardless of whether Covid-19 was identified at a NH or not. Several family members described the restrictions as too rigid, without any form of flexibility, a sentiment echoed by some of the staff members, who explained that they had to choose caution when in doubt. During the second lockdown, family members said that their lack of access to the NHs started to have dire consequences, for them and for the residents, who somehow started to accept the situation, in a form of resignation, leaving them more passive and less contact-seeking. As one of them explained, their family member gradually went from calling five times a day to once every other week, “perhaps because he is sitting by himself all the time and forgets.” A physician explained that such passivity also affected residents’ health: “It was a great concern, and it still is. You know, in geriatrics we are very concerned with movement, physical therapy and exercise to maintain bodily functions, and also to avoid things like edemas, right. To ensure movement of saliva that
can cause pneumonia. So, I have been worried about residents becoming too passive.”

When visits were allowed, limited access inside the NHs made it difficult for visitors. Family members could only use selected entrances, there were guidelines for where and how they could move around, and they had to avoid common areas. Having large, single rooms was highlighted by some family members as important in a situation where they had to spend all their time inside residents’ rooms. Still, several family members described how residents gradually lost hope: they were isolated in their rooms and NH staff had to prioritize the “absolute necessities,” and social activities and interaction were not prioritized. As one nurse explained, secluded residents sought contact with nursing staff in different and new ways, sometimes out of boredom: one resident, for example, habitually called for a nurse to ask what the weather was like.

In spite of the difficult situation, various creative solutions to circumvent what were perceived as strict but necessary restrictions were put in place:

- At one NH, a tent was raised outside the building. It functioned as a form of air lock where residents and family members could meet in a safe place.
- Concerts were arranged outside one NH.
- Staff helped residents use tablets, to allow family members to “see” the residents.
- At one NH, each ward allocated one staff member to be a “coordinator for leisure activities.”
- At one NH, Sunday church services were streamed from the church to the NH.

Still, as family members explained, these solutions were not adequate: nothing could replace meeting your loved ones. And rather than meeting with staff, family members had to communicate by telephone.

Staff at NHs represented a particularly vulnerable segment of health care workers during the pandemic (Molvik et al., 2021), in part because they were in constant contact with many potential carriers of the virus. This led to strict protocols of isolation and self-isolation for workers, often leaving NHs short-staffed. Attempts to limit the use of agency/temporary staff added to this difficult situation. Several managers explained that a precarious staff situation was reinforced by the fact that several staff members were employed in limited, part-time positions.

In some of the NHs included in our study, many staff members worked part time in several NHs or in other sectors. Management stressed how part-time positions made them particularly vulnerable. Consequently, some NHs sought to improve staff continuity and consistency. At one NH, for instance, staff
employment at other NHs was forbidden, and staff members were offered extra shifts to ensure as many working hours within one NH as possible. This was accomplished through collaboration with municipal administrations as well as with other NHs in the municipality; at another smaller NH this didn’t happen, to the frustration of many staff members. The institution implemented a routine of a “complete body and hair wash” for staff when moving between workplaces, but this was described by other staff members as inadequate.

As a result of these conditions, boundary work for NH staff occurred in two primary forms: allocation of work within certain physical areas/wards, and a shift in the division of labour. For example, at a large NH, staff working directly with social activities were assigned to other tasks more aligned with the new routines, such as preparing baked goods and treats to be served directly to the residents in their rooms. More importantly, auxiliary nurses at several NHs were handed responsibilities usually assigned to registered nurses. And at one NH, assistant nurses with unrecognized degrees in registered nursing from a foreign country were given temporary accreditation but were not economically compensated for their new responsibilities. At another NH, they used a pool of temporary staff familiar with the NH to accommodate the absence of regular staff.

Our research describes how efforts and work shifted towards certain areas and wards. At one NH, measures were implemented to solve staffing issues due to contagion in one ward. As staff members explained, the ward in question was quickly “shut down.” Only designated staff could work there. These staff were not permitted to leave the ward during their shift, and routines for delivering equipment and food were set in place. This was described as efficiently executed, thanks to a resourceful manager. Similarly, in another NH, the manager, in collaboration with the ward leader, chose their “best people” to serve in the infected ward. They were mostly young registered nurses and other nursing staff that the managers thought would be capable of working under demanding conditions. Some of the registered nurses moved temporarily from another ward at the NH.

More registered nurses were allocated to the isolated wards and, consequently, there were fewer RNs at others. In general, this concentration of efforts led to “less time for residents.” As one nurse explained: “They [residents] have felt the effect of auxiliary nurses who have worked on the floor having been busy with other things. They have to wait because of extra tasks delegated to those nurses. So they have felt that part, yes.” A manager expressed that, due to isolation and quarantine, some regular nursing staff also had to take the position of ward leader, further shifting responsibility in a fragile staff arrangement. The manager noted that working on infected wards was demanding and not suitable for everyone. Not just formal competency, but personal preferences and experiences were important: “For some, it has been
a very tough situation,” alluding to the potential for subsequent work-related sickness leave. The movement of staff and the concentration of “competent” staff members in some wards at some periods of time, were, in other words, a consequence of shifting boundaries in the NHs, experienced as necessary, but creating other challenges.

**BOUNDARY WORK AT WHAT COST?**

Our research indicates that the built environment of NHs presents both barriers and opportunities for handling a pandemic. Perhaps most importantly, the practices of creating, maintaining, and adapting inside and outside boundaries are as challenging as they are essential. Anderson and colleagues (2020) argue that the permeability of NH boundaries can be seen as an indicator of the quality of social life in the institutions, with openness and flow as an ideal. With this perspective, the quality of what is contained within the boundaries depends on how the boundaries allow a flow of people, information, and objects. Hence, and not surprisingly, the opportunity for a meaningful and dignified life in NHs has been put to the test during the pandemic.

As our research shows, the built environment does not work in a one-way direction, determining what takes place on the premises. The various “players” at NHs also influence and adapt to their physical environments, and, at least to some extent, continuously mould and change them. Still, there is ample room for improvement in how NHs work as a built environment for the frailest and most vulnerable older persons and for those who work in and visit them. We have highlighted the difficult balancing act between infection control and supporting activities and a meaningful social life, and this is also an important topic in the research literature.

Anderson and colleagues (2020) point out that a balance must be struck between infection control and other important concerns related to health and well-being, such as access to and use of common areas. Research reinforces our findings on how residents suffered during the pandemic, not only from a deterioration in physical abilities and cognitive functioning, but from loneliness and unmet social needs (Lood, Haak, & Dahlin-Ivanoff, 2021). Furthermore, the pandemic has affected the health and well-being of NH staff as well as their working practices (e.g., Hanna et al., 2022), and caused burnout among the nursing staff (Yau et al., 2021). These findings seem to indicate that it is not just the characteristics of the facility but the ongoing “battle” with the pandemic and the institutional practices that occur when there is infection that matter.

This is supported in our material, where the allocation of staff at certain time periods and in certain spaces has led to a shift in responsibilities both vertically and horizontally. These efforts were successful in some ways, at least from
the perspective of infection control: some NHs managed to prevent infection from entering their NH, and the NHs with infection in certain wards managed to prevent it from spreading to other wards. Boundary work outside and inside was, in other words, both novel and effective. Still, we ask, at what cost for residents, families, and staff?

NH staff were described by one family member as committing “heroic deeds” during the pandemic. Yet the strict boundary work related to the outside of the NHs led to boundary maintenance inside, implying greater strain on staff and less attention to the social needs of residents. In combination, this represents a fragile and unsustainable system. NH staff experienced the situation as difficult and, as alluded to in the introduction, as far from a “dugnad,” or voluntary good work, and more as a way in which their skills and professionalism were put to the test. Working with infection control, through what we perceive as complex and changing boundary work, was demanding, not only when protecting the NHs from the dangers outside but also when leaving the homes. Several nursing staff members experienced a form of stigma from the outside community whereby “civilians” (as well as staff working in “safe spaces”) were suspicious of the danger they represented. This led to feelings of anxiety and, for some, prolonged sick leave.

Considering the huge amount of skilled work required of NH staff, and their commitment, compassion, and resilience in light of the dangers they endured, the lack of recognition of their work is both puzzling and unfortunate. The need for safe and adequate working conditions, not least through permanent and full-time positions, has been undeniably reiterated by the pandemic and the boundary work following it.

NOTE

1. “Dugnad” is a Norwegian term etymologically derived from the Norse word dugnaðr, meaning “help” or “support” and referring to civic acts of unpaid efforts meant to serve the greater good. The Norwegian minister of health at the time, Bent Høie, made a call for a “national dugnad” at the beginning of the pandemic. This statement is a response.

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6. Are safer, welcoming care homes possible? Considering physical environments

Susan Braedley and Pat Armstrong

Concerns about care homes’ physical environments emerged as the pandemic rolled through care homes across jurisdictions. Did overcrowding, close quarters, large facilities, and shared spaces create the conditions for high rates of resident infection and death? Advocates have argued that infection control would have been easier and isolation measures less restrictive if residents had individual “apartments” complete with a bathroom, rather than the shared rooms common in some jurisdictions. Others maintained that many care homes are too big. Smaller homes would mean fewer people involved and lower risks. A third group argued that care homes should be abolished entirely, in favour of home and community care.

While intended to advance care possibilities, these critiques fail to examine resident, staff, and family experiences of care home physical environments during the pandemic. What has the pandemic revealed about these physical environments that could lead to safer, respectful, dignified conditions of living, working, and caring? In this chapter, we take up this vital question. Our definition of physical environments includes the location of the home relative to the communities it serves, and its size, design, and structure. We consider the gardens and outdoor areas, how the home is furnished and decorated. Most importantly, we consider the physical environment from the perspectives of residents and workers, who know how they interact with and use these physical environments in their living and working.

Drawing on a physical design analysis of photo diaries and interviews at eight care homes in Ontario, Canada’s largest province (Trudel et al., 2022), we begin by describing how residents, staff, and families experienced care home environments since the onset of the pandemic. We take readers on a “tour” of a composite, representative care home we developed from this analysis, showing the changes shaped by the incessant fluctuations of lockdowns, restrictions, and physical distancing measures. Next, we consider the variety of care home physical environments across contexts, and factors implicated in
Are safer, welcoming care homes possible?

different design choices. Finally, we draw on over a decade of international care home research to outline six principles for planning and organizing the future of care home physical environments.

Throughout the chapter, we develop one overriding argument: There is no single “best” way to organize care home physical environments for all those who need 24/7 medical and social care (Armstrong & Braedley, 2016). However, using the principles we outline, care home environments can be organized to provide respectful, safer, dignified conditions of care, life, and work across communities and jurisdictions.

A CARE HOME PANDEMIC WALK-AROUND

Our composite care home is Parkview, located on a busy city street in a lively, mixed-use neighbourhood of one of Ontario’s big cities. It holds just over 200 beds and has a good reputation. Stores, schools, a park, apartment buildings, and other housing are located close by. Bus stops are just steps away, but car parking is expensive, limited, and short term. Nevertheless, fears of infection on public transit have meant more workers and visitors are choosing car travel when possible.

During the first two years of the pandemic, Ontario had one of the highest care home resident rates of death among OECD jurisdictions, with care home residents 13 times more likely to contract and die from Covid-19 than other people 69 years and older (Akhtar-Danesh et al., 2022). At Parkview, two-thirds of their residents and many of their staff were infected in the first year, but only ten residents died from Covid in 2020–2021. The home has had many outbreaks since 2020, with government lockdowns and restrictions that have required changes to protocols, signage, and use of the physical environment. In 2022, Covid outbreaks and occasional lockdowns continued, but residents’ designated caregivers could visit as long as they tested negative for the virus.

Our tour begins at the main entry, where we are met by the infection control manager. She tells us that all of Parkview’s entry areas are poorly designed for infection control demands. As soon as the pandemic restrictions began in 2020, wet footwear and worried workers made big messes in entry ways, creating extra work for short-staffed housekeepers. She shows us a “screening station,” where staff, family members, and visitors are assessed for Covid. It takes up almost all the space in this designated entry. Other entries have been locked. Initially, even on freezing winter days, staff and family visitors had to stand outside in the dark of early mornings and evenings, waiting for test results before starting their shifts or entering care homes. Some care homes set up outdoor heaters to help reduce the chill, while some developed “drive-thru” testing/screening systems. At Parkview’s site, staff line-ups blocked city...
sidewalks at shift changes, prompting the home to repurpose an activity room near the main entry. This became a worker-only “screening area” organized to screen 70 workers in 90 minutes.

We walk single file down the rather dim hallway, as one wall is lined to waist height and even higher with boxes of supplies. The infection control manager explains that the care home was not designed to store the volume of infection control supplies needed during the pandemic. Trucks deliver the boxes on wrapped shipping pallets, leaving them at a small docking bay, so even getting them into the building is a big job. This home has coped by repurposing office areas, linen storage, and hallways for storage. This hallway storage is against fire code regulation, but with space and labour in short supply, there is no other available space. Moving the boxes is complicated. Residents and staff cannot physically distance if there is two-way traffic, and the infection manager points out that the hallway is very difficult to maneuver with a large bariatric wheelchair.

The hallway is also plastered with signs explaining pandemic-related safety procedures. Bulky holders for personal protective equipment (PPE) hang outside each of the 24 resident rooms on this floor. How to dispose of the PPE is a problem, we’re told, as the available containers and systems were not large enough to hold the waste. And the manager says she has redone the signage so often that “signage fatigue” has hit the staff; she is pretty sure they do not always notice the frequently changed protocols on the signs. The messy, crowded walkways, signs, and supplies give us a sense of a medical workplace, not a place where people live.

We leave the manager to be joined by a care aide who knocks on doors to ask residents if we can visit. In one double-occupancy room, we meet a happily married couple who explain that being able to be together has kept them going during the frequent lockdowns. “We are lucky. We have each other!” In another double-occupancy room, we meet Ruth and Vivian. Ruth tells us she enjoys the companionship of a roommate. She grew up in a large family and has never lived on her own. Vivian explains that being useful to another person is important to her. She likes helping Ruth to use her cell phone, to straighten out belongings, and to remember activities.

Other residents tell us they enjoy and prefer their private rooms. Donald says he sleeps better without another person’s noises and habits. He appreciates the privacy of his own space. We notice that all the rooms are relatively small and sparsely furnished with mostly hospital-like furnishings. There is little space for residents’ own furniture or belongings, although some residents have an easy chair and a computer or television. None of these rooms is designed to be a space for sleeping, living, entertaining, and dining, although during lockdowns this is the residents’ reality. There is almost no storage for personal items such as hobby supplies and other pastimes, and insufficient room for
Are safer, welcoming care homes possible?

a small seating area for meals or visits. The room lighting is overly bright and harsh. Some residents have brought in lamps, but electrical outlets are few, so some residents have not been able to organize softer lighting. Only a few of the windows open, and these open only slightly. In many resident rooms, the windows are both high and poorly located, so that a person in a wheelchair or in bed cannot see out at all, and even a standing person cannot see down to the ground outside. Being able to see what is happening outside the home can change life for residents, especially when visitors are restricted. As one family member who installed a bird feeder outside their resident’s well-situated first-floor window comments, “Now she’s in heaven when she looks up to this bird feeder, but also there’s lots of trees and shrubs and flowers outside the room that she can look at.”

Residents tell us they are unable to regulate the temperature or air quality in their rooms to deal with being too hot or too cold. The noise levels are also high. You can clearly hear a conversation in the hallway and the loud rumbling of laundry carts going by. Residents and family tell us there are sometimes unpleasant odors from soiled linens, disinfectant, food, and garbage.

We walk through a lounge area, a resident kitchen, a small library, and a dining room. All these areas were closed or repurposed at the height of the pandemic. Some have moved back into use, but some are still used for storage. The care aide tells us that most upholstered furniture was removed from shared spaces at the onset of the pandemic, due to concerns about infection control, and has not been returned or replaced. Prior to the pandemic, four residents sat at each dining table, but new distancing measures mean that each table can have only two residents, and so twice as many tables are required. The existing dining area is too small to allow for this arrangement, so now the lounge is a dining area as well, repurposed for physically distanced dining.

We notice a door out to a small patio and grassy lawn with flowers, shrubs, and trees. Since the onset of the pandemic, outdoor spaces have taken on heightened importance for residents and family members. In some homes, outdoor visits were allowed when other possibilities were restricted. In this home, the small outdoor area is mostly inaccessible during the winter and early spring, as shovelled snow from walks and doorway areas is dumped there. Second, its grassy area is too uneven for wheelchairs, and there is no secure outdoor area suitable for people with dementia to venture out unaccompanied. Prior to the pandemic, many residents made use of the adjacent park and busy sidewalks, stores, and restaurants for outings, often with help from staff and family members. But pandemic rules restricted these options, keeping people inside.

Next, we enter a narrow, shared staff space, situated near the elevator. A long counter, lined with computer stations, forms a barrier between this space and the hallway. This area is where nurses and care aides “chart” their
work and store their records. A locked medication room, a staff washroom, and a small closet are tucked in behind the computer desk area. The design does not allow for physical distancing, as workers must pass directly behind other seated workers to get to workstations, the washroom, and the medication room. Staff explain that this space is also sometimes used as a storage area for PPE and other supplies, for linens, and for storage carts.

Although the counter is low and open to the hallway, computer equipment and files are organized so that residents and staff cannot easily see each other when staff are seated. However, staff often “park” residents in wheelchairs near this area, keeping them close at hand while they “chart.” Other residents tend to gather nearby, watching staff at work and making conversation. Staff often negotiate a maze of people and wheelchairs to get to this staff space. We note that the small closet contains a stool and cushion, as well as supplies. A care aide tells us they use the closet for breaks. The staff break room is in the basement, and with short staffing one worker leaving the resident floor puts undue pressure on the workers left behind. Taking a short break in this closet means they can quickly respond if another worker needs assistance to support residents, but it also means they never completely disengage during shifts.

We try to stay on the one-way path that has been created through the home to help with physical distancing. We push through heavy doors, go up a ramp into the next unit, then push through more heavy doors to return to the lounge area of this unit. For staff, these extra steps, time, and doors have made everyday tasks much more difficult. They admit that they often ignore the one-way rule. For residents, the one-way path is impossible. The heavy doors can be opened with automatic openers, but the doors open and close too quickly for most residents using walkers or wheelchairs.

We end our tour near the central lounge area. The washrooms in this area are locked and have not been open since before the pandemic. Closed initially because of infection control worries, then kept closed due to lockdowns, they remain closed to residents and family members because of staffing shortages. Managers have looked for small ways to reduce workloads, to ensure residents get the care they need. But this means that if a resident is in the lounge area and needs a washroom, they must return to their own bedroom. Two residents tell us this keeps them from using this lounge, as they are worried about having an accident and being embarrassed.

Parkview’s physical environment is representative of the eight care homes included in this small study and of many other Canadian care homes included in our larger team’s research. While its physical environment’s shortcomings were apparent before the pandemic, pandemic conditions revealed ways in which its design does not promote safe, dignified, respectful conditions of living and working. Storage for resident belongings and care home supplies is insufficient and inconvenient. Hallways are too narrow, too long, and do
Are safer, welcoming care homes possible?

not facilitate traffic flows of workers, wheelchaired residents, and necessary equipment. Ventilation, heating, and cooling are not designed to offer comfort in individual rooms and spaces. Windows and outdoor areas are poorly designed for the population who lives here, restricting not only their opportunities to go outside, but their views of the world outside the home. Staff areas are neither convenient nor well-organized. Parking costs are high and all-day parking is sparse for staff and visitors arriving by car.

Some aspects of the Parkview environment work very well, however. Having some double rooms offers opportunities for companionship to those who prefer to live with others, including spouses. While allowing some risk of infection, these rooms also alleviate the social isolation and loneliness that affected the health and well-being of so many residents during lockdowns. Private rooms offer quiet, good sleeps and privacy for many residents. Flexible spaces throughout the home were easily repurposed – for screening and for distanced dining, as two examples – allowing for better care. The home’s central location, proximity to bus stops, shops, and a park make life easier for staff and visitors who travel on public transit or live within walking distance. Workers lunch in the park in good weather, and visitors regularly take residents out into the neighbourhood, including with wheelchairs and walkers that easily negotiate the city sidewalks.

Finally, pandemic conditions demonstrate clearly that staffing levels are critical to maintaining a functioning care home environment. Infection control protocols, combined with staffing shortages mean muddy, slippery entry ways, cluttered and unsafe hallways, locked bathrooms in public areas, more carts left in hallways and outside of elevators, and more odors and mess throughout the home. Notably, it is staff who innovate to repurpose space and work to make residents more comfortable under these difficult conditions.

WHAT MAKES FOR A GOOD CARE HOME PHYSICAL ENVIRONMENT?

Given the Parkview portrait which reveals many typical problems, what are the characteristics of a care home physical environment that offers conditions of safety, dignity, and respect for residents and workers (Armstrong & Braedley, 2016)? Ideas about what makes for a good care home have shifted over time and across jurisdictions, and will no doubt continue to do so (Braedley, 2018; Struthers, 2018). Across and within contexts, care home physical environments vary dramatically. Some care homes are immense high-rise facilities with large hospital-like “wards,” some are single storey with apartment-like arrangements. Some homes have small rooms for residents with large comfortable shared areas, to encourage social interaction. Some have large, per-
personalized rooms where residents spend most of their time alone, facilitating rest and privacy.

Care homes are located within communities in different ways. Some care homes are seamlessly integrated into urban streetscapes, some are connected to shopping malls, day cares, hospitals, and community centres, while others are in pastoral surroundings or located along busy suburban highways in the outskirts of cities and towns, without public transit. Increasingly, care homes are one component in a “campus” of care that typically includes a retirement home, a day program facility, and other forms of assisted living.

Care home décor also runs a wide gamut, from “health care institutional” to contemporary modern to antiques and kitsch. In our research across many jurisdictions and a wide range of home locations, sizes, styles, and décor, residents, staff, managers, and families usually had strong opinions about what worked best for care home décor, and there was little consensus across contexts.

Like all buildings, care home physical environments are affected by real estate conditions. Building codes, land use regulations, financing costs, increasing financialization (August, 2021, 2022; Harrington et al., 2017), and the costs of land, building supplies, and labour all have their influence. For example, in Texas our team encountered a competitive care home market. Many care homes were reluctant to accept residents funded by Medicaid, a program that paid a reduced rate, and instead targeted their marketing to wealthier individuals and referring physicians. In this context, care home physical environments were an important marketing tool. Inside one home, a grand piano and chandelier offered visitors a first impression of luxury and culture. Another home displayed large apartment-style rooms and an elegant restaurant-like dining area. Across our research sites, we noted that in locations with lower land prices, care homes were often low-rise, sprawling, and had significant outdoor areas. In urban areas with higher land prices, care homes were organized in the same way as other housing: high-rise and with little or no outdoor areas.

Care home physical environments are also influenced by culture, usually reflecting the dominant culture of their communities. In our research, for example, the shared spaces of a dementia-specific care home in England expressed a local Anglo-cultural aesthetic of domestic, cosy comfort. The home had brightly painted walls in contrasting colours, pictures and bric-a-brac on every wall, tables covered in knick-knacks, toys, and plants, and sofas plump with pillows and blankets. This physical environment, touted as a stimulating, happy, even therapeutic environment for the residents, was unacceptable to Scandinavian researchers, whose cultural understanding of dementia care required calm, tidy surroundings that English researchers might find boring or bare. Care home residents and worker populations reflect the diversity of
contemporary societies, with a multiplicity of ethnicities, cultures, religions, sexualities, and gender identities sharing space, life, and work each day and night (see Chapter 9). The cultural assumptions built into care home physical environments can produce unwelcoming, even unsafe conditions for those whose culture, community, or identity is not reflected (Braedley, 2018; Streeter et al., 2020), leading to questions of how best to provide a welcoming care home physical environment to support rapidly shifting and increasing heterogenous populations of residents and staff.

Finally, societal, government, insurance industry, owner, and medical experts’ perspectives on safety and risk influence what counts as a good care home physical environment. Most people agree that care homes must be safe places to live and to work, that surfaces must be easy to clean and maintain, that floors, door openings, and tables must accommodate wheelchairs easily, and that bedrooms and bathrooms should be designed to make lifts safe for both workers and residents. But what counts as safety is too often interpreted as the elimination of risk. Residents’ choices are sometimes limited to reduce liability concerns, satisfy insurers, and minimize family worries. We have seen exterior doors to fenced, secure outdoor areas kept locked, to prevent residents from leaving the building without a staff member. Yet to ensure that staff always have easy access, residents were not permitted locks on their rooms, even though these unlocked rooms afford easy entry to other residents and deny a resident’s right to privacy, including for sexual activities (Daly & Braedley, 2017; Tufford et al., 2018). Care home regulations often “build in” other safety measures, such as requirements for fire doors with automatic openers that close too quickly for residents to get through. At the same time, some risks to residents’ autonomy and mobility are forgotten or ignored in design. For example, we have encountered chairs without arms needed for leverage in moving from a seated to a standing position. We have seen soft carpets that hinder wheelchairs. Care home physical environments must balance residents’ rights – to privacy, to fresh air, to mobility, to exit, and to control over their personal space – with safety and ease for both residents and staff.

With these variations and influences, there is no easy or single answer to the question of what makes for a good care home physical environment. In our research, we found ideas worth sharing and ideas to leave behind in most care home physical environments.

A FUTURE FOR CARE HOME PHYSICAL ENVIRONMENTS: SIX PRINCIPLES

Our analysis has led us to identify six principles underpinning physical environments that offer safer, dignified, respectful conditions for residents, staff, families, volunteers, and community members. In developing these principles,
we do not side-step or ignore the many tensions that care home design must straddle. Instead, we believe these principles offer an approach to balancing these tensions, although we recognize that these tensions vary from context to context.

**Principle 1: Consider the Perspectives of those who Live, Work, and Manage in the Care Home**

This principle runs through all the others and is central to our research findings.

This principle means attending to those who live in care homes, paying close attention to the differences across jurisdictions and communities. In high-income jurisdictions, care home residents are being admitted at older ages, with more complex health conditions and advanced dementias. They are also overwhelmingly women. But these are not the only people served by care homes. For example, in Canada, many people as young as 18 years live in care homes (Barber et al., 2021; Shieu et al., 2021). Young people who need 24/7 care are hampered by physical environments designed for residents who are mostly 85 years or older. While we question why young disabled people in Canada have no alternatives to care homes, there is a failure to consider and include them in care home physical environment design.

Who needs care homes, as opposed to who lives in care homes, must also be considered. LGBTQ older adults avoid care homes despite care needs, due to homophobic and transphobic organizational practices that encourage LGBTQ residents to “go into the closet” (Brotman et al., 2015; Löf & Olaison, 2018). Immigrant older adults are less likely to use care home services in many jurisdictions (Durst & Barrass, 2014; Koehn et al., 2018), especially when experiencing dementia. Adding to concerns about culture and racism are issues of language, as dementia-affected people often lose the use of languages learned later in life, retaining only their cradle tongue. While physical environment design alone cannot address these exclusions, it can facilitate conditions that support safer, accessible care.

Culturally-specific care homes have operated for many years in some contexts. Most of these homes have been developed and operated by the communities they serve, such as the Jewish care homes our team members have visited in Canada, the US, and Sweden. In these homes, physical environments include kitchens set up to offer kosher dining and common rooms organized to allow residents and staff to maintain religious and community traditions. Symbols and signs of Jewish tradition and culture are visible throughout the homes, and the artwork and décor reflect the histories of Jewish communities in these contexts.

Some care homes are designed to offer care to a variety of designated cultural and linguistic-specific groups. For example, one municipal home in
Ontario has a Cantonese, a Farsi, a Korean, a Mandarin, and a Jewish unit. A non-profit home offers a specialized unit for LGBTQ residents. Physical environment matters in the creation of these designated spaces, via signage in a variety of languages, and artwork that, for example, includes same-sex couples. Some homes include gender-neutral washrooms, places for spiritual practices, and choices of fabrics and design elements that reflect and include the many communities involved in and surrounding these care homes.

Learning about what works for residents is not difficult, although it is often neglected. In our research, residents in late-stage dementia at a home in the UK communicated what they wanted by repeatedly choosing a bright, circular pathway as their favourite stroll. At a home in Ontario, residents with dementia spent many hours in the cosy “bird corner,” where small, bright birds chirped from cages installed so that seated residents could see the birds but not touch them.

Although managers and nursing supervisors often have the most control over design decisions, staff perspectives are crucial to physical environment design (Choiniere et al., 2010). For example, in planning a new dementia unit at an older care home in Canada, housekeepers and maintenance staff pointed out that the recommended floor materials would make cleaning harder and more expensive. Nurses asked for clearer sight lines, and a discreet white board in the staff area to support staff communication. Care aides advocated for easily accessed, easily maintained closed storage for continence supplies and linens. One care aide proposed different coloured doors for resident rooms, to help residents wayfind and identify their own rooms. Another care aide suggested placing large name plates outside resident rooms that included residents’ preferred names, so that staff, visitors, and other residents would know how residents liked to be addressed.

**Principle 2: Consider Location, Space, and Size**

Location, space, and size are enduring aspects of physical environments. And while buildings can be renovated and changed, location is permanent. Location is also critical to care (Lowndes et al., 2021). Is the care home located conveniently for staff and visitors? Is it situated where residents can participate in some community life, or at least see an activity taking place?

Considering space is important, too. Do spaces accommodate large bariatric wheelchairs, lifts, and traffic? Do resident rooms allow space for quiet visits, hobbies, and dining when necessary? Is there space in the washroom for a two-person lift from the toilet, or is the washroom too small and the toilet positioned too close to the wall? Can residents and staff move easily through the home, or are there locks on doors, barriers to going outside, and restrictions on common room use (Tufford et al., 2018)?
Storage for resident belongings and staff supplies is frequently insufficient and inconvenient, and needs much greater attention, as the Parkview example demonstrates. Flexible spaces are extremely useful, allowing care homes to adapt to changing needs and conditions, and to promote connections with the community. For example, in Germany, one care home offered a multi-use room to a community music group for their weekly rehearsals – in exchange for regular concerts.

And in considering space, resident and staff perspectives remain critical. For example, one care home’s well-appointed common area was designed to offer expansive window views of a peaceful, beautiful countryside. Few residents spent time there! Residents preferred to gather near the front entry that looked out on a grim parking lot, enjoying opportunities to interact with the staff and visitors moving through this space. The common area, while pleasant, was too quiet and lonely. This was the case in many care homes we visited across contexts (Ågotnes & Øye, 2018).

Size too must be considered. In our research, care home units with six to nine residents often seemed too small, as there were few visitors and as boredom with the same small group of residents and staff set in. In one Nova Scotia home, a substantial number of deaths occurring over a short time in a small unit left its entire staff and surviving residents grieving and traumatized. But units with more than 20 residents often seemed too impersonal, too busy, and too institutional.

Large homes containing many small units were one way that organizations balanced size tensions. A larger home offers many economies of scale, including opportunities for more community spaces. But small units offer more enclosed, familiar spaces, fewer people, and opportunities for relationships to flourish.

**Principle 3: Consider Relationships, Connection, and Privacy**

Throughout our research, we consider care as a relationship (Armstrong & Braedley, 2013). Care home physical environments must be designed to support relationships of many kinds. For example, relationships between residents in a Canadian home were facilitated by a living area with many small tables and flexible seating areas. Used to hold a weekly Happy Hour, the tables were set up with board games, cards, puzzles, and crafts. Residents mingled and participated in the activities as they chose, sharing snacks and engaging with each other on their own terms (Ågotnes & Øye, 2018). Relationships among residents in a Norwegian nursing home were facilitated by unit dining rooms with one large family table. Eight to ten residents had regular mealtimes together, developing relationships through daily talking and bickering as they got to know each other (Ågotnes & Øye, 2018).
Support for relationships among staff is also important. In Sweden, a bright, tidy staff lounge with sparkling water dispenser, coffee machine, microwave, fridge, and comfortable armchairs facilitated staff relationships and teamwork, as did the pleasant meeting room used to hold regular “reflection” meetings with nursing staff.

Physical environments can also cultivate relationships among staff and residents, and connections between residents, their families, and their communities. In a Nova Scotia home, the absence of nursing stations meant that nursing staff completed their charting on touchscreen tablets in lounge and dining areas, facilitating conversations with residents and visitors. In Norway, a care home was located in a building that included a day care centre, the public swimming pool, a cafeteria and a spa, stimulating continual community exchanges. An Ontario care home has a small pub area, staffed by volunteers every afternoon. It is a favourite spot for family visits.

Considering relationships means ensuring capacity for communication technologies, for both residents and staff. Access to internet Wi-Fi and technology for video-calling is now an essential support for residents, especially when they are prevented from seeing visitors, or even other residents, during lockdowns. Yet many care homes have not yet organized Wi-Fi throughout the home.

Considering relationships also means attending to privacy needs. Are there resident spaces that allow uninterrupted privacy for rest, visits, or sexual activities (Daly & Braedley, 2017)? How is space arranged to ensure privacy and dignity for toileting, continence care, and bathing? Are residents able to secure their space, so that other residents cannot wander in and remove items? Without these kinds of privacy, both intimacy and trust are undermined, putting strain on relationships that residents need to sustain them. Staff also need privacy. Where can staff have a confidential conversation about a worrying situation? Where can they go to recover, if overwhelmed by emotion? Where can staff change into their work clothes, and keep their street clothes and other belongings secure?

**Principle 4: Consider Frailty, Disability, and Dying**

For all care home residents, frailty and disability are constant realities. Regulations and design for care home physical environments sometimes ignore this fact, as Parkview’s heavy doors and narrow, dim hallways demonstrate. Frailty means bodies have reduced tolerance for cold and heat, but homes often centralize climate control. With climate change, air conditioning is becoming essential even in homes located in northern regions, yet it is not always available.
Considering disability means enabling the autonomy of residents, not restricting it. It means problem-solving to ensure that people with widely differing abilities can use light switches, taps, kitchens, closets, toilets, and more.

Considering dying is also essential in planning and organizing physical environments (Banerjee & Rewegan, 2017). End-of-life care is a significant part of what care homes offer (Schwellnus et al., 2021). Are there private, comfortable spaces for quiet conversations about dying and resident preferences for end-of-life care? Are there rooms for family to stay on site when their loved one is near death? Is there a memorial space for residents to be remembered by staff, residents, volunteers, and family? Is there dedicated space for spiritual practices that can adapt to different faith traditions? How are residents’ bodies removed after death? In many homes, hallways and doors are arranged to whisk the stretchers holding the bodies of deceased residents out a back door. In a Canadian home, the physical design allowed for residents’ bodies to go out through the front door, covered in a special quilt. This process was conducted with a short but moving ceremony that accorded dignity and was much appreciated by staff and residents.

**Principle 5: Consider Dining, Meaningful Activity, and Sensory Pleasures**

Considering dining, meaningful activities, and sensory pleasures means attending to how a physical environment can stimulate our senses, awaken our interests, and create moments of pleasure. A garden area surrounding a Swedish home, for example, offered bird song, rich colours, a tinkling fountain, the textures of grass, stone, and wood. Residents can walk, wheel, and enjoy a beverage in this area. A gardener looks after it, ensuring it is accessible and beautiful. In a home in the UK, a bright windowed corner has classical music, flowering plants, and furniture arranged to accommodate large wheelchairs. It is a favourite spot for very frail residents who enjoy the music, flowers, and sunshine.

Dining is a central daily activity in every care home we have studied (Lowndes et al., 2018). Pandemic conditions have made it clear that dining needs more attention in care home design. Are there options for safer dining spaces that can be organized in outbreak conditions? Are dining and cooking spaces organized so that residents have opportunities to smell food cooking, see fresh tempting food, even participate in food preparations? Are there spaces to offer snacks, coffee breaks, or a cocktail hour between meals? As dining is most pleasurable when we share it with others, do spaces accommodate community involvement?

Pre-pandemic, we studied care homes in Nova Scotia, Ontario, and Norway that offered a regular affordable “lunch” for people from the community,
who shared food and company with residents. These programs were possible because of kitchen design and generous flexible spaces, and it is hoped they can be resumed. In Germany and the UK, we observed meals being prepared in domestic-style kitchens adjacent to dining areas. The kitchens were organized to include residents, who cut vegetables, loaded the dishwasher, and made toast. In western Canada, a care home kitchen is designed to accommodate community members as cooks, as we learned when a community group prepared a meal with residents and had a lively discussion on how best to form the egg rolls!

Physical environments can support meaningful activities like these for residents. In some care homes, residents may be persuaded to do relatively meaningless activities: to colour in colouring books, fold and refold a pile of towels, or watch old movies. But well-designed physical environments offer more meaningful activities. A “men’s shed” in a Norwegian home includes a bicycle that one resident loves to tune up. A Canadian home has a few wheelchair-accessible golf holes enjoyed by both residents and visitors.

**Principle 6: Consider Food Preparation, Cleaning, and Laundry**

Considering main kitchens, laundries, or maintenance areas is essential to care home physical environments. In our international research, we spent many hours in them, job-shadowing cooks, housekeepers, and laundry workers.

We learned that considering spaces for food preparation is critical to residents’ experience of dining. In Sweden, a chef oversaw his team’s food preparation in a spacious, airy commercial kitchen on a lower level. Workers transported the dishes prepared for each meal to each unit’s domestic style kitchen in temperature-controlled carts. Assistant nurses laid out the dishes buffet style, ensuring that the temperature was correct. They transferred sauces to small pitchers and arranged the food to look appetizing. Each resident chose what they would like from the choices and determined the quantity on their plate. Between meals, workers baked muffins or other treats in the well-equipped unit kitchen, filling the unit with delicious smells, sights, and tastes. Compare this example with an Ontario home in which food came up to a small dining room airline-style, with cling-wrap covering an often-unappetizing meal prepared by food workers in a dingy basement kitchen. While a fridge, microwave, dishwasher, and sink were organized at one end of the dining room, there was no space and no supplies for cooking or for in-between meal snacks. The dining experience was shaped by poor design.

Considering laundry is also important, for infection control, for resident comfort and self-respect, and to support workers whose work includes bedding, towels, and clothing (Armstrong & Day, 2017; Müller et al., 2018). In a bright, well-ventilated laundry in Nova Scotia, industrial machines were installed at
waist height to reduce injury. Folding tables, trolleys, and hanging racks were organized so that clothes were easily sorted and labelled for each individual resident, and clothing was kept separate from heavy laundry that required more disinfection. There was a generous sink area where more delicate clothing was washed by hand and hung to dry. Although in a lower level, the room had an exterior window and windows out to a hallway, so that workers were not isolated from others. The laundry workers were understandably proud of their work and their workspace. Quite different were homes we studied in Sweden, where residents’ personal laundry was done by care aides in small laundry areas located in each resident’s room. Residents and families could also use these laundries. Both systems worked well, but relied on different physical environments, divisions of labour, and approaches to care.

Cleaning is a top priority in care homes (Müller et al., 2018), and an important consideration for physical design. Infection control for frail residents with compromised immune systems means that care homes must be kept cleaner than a private home or hotel. And, due to disability and frailty, residents are more likely to make messes as they go about their daily lives. Easy clean-up supports their dignity and encourages them to continue participating in activities. Choosing easy-to-maintain surfaces that are also attractive is a challenge but it is possible, as our site studies have shown. Ensuring clean air can be achieved with quiet, well-designed ventilation systems. Well-planned garbage and laundry collection systems support workers to easily remove soiled linens, continence products, and other waste from resident home areas to utility areas in closed containers. Considering cleaning also ensures that cleaners have sufficient, safe, and pleasant-to-use cleaning products and equipment to make cleaning easier and safer.

ARE SAFER, WELCOMING CARE HOMES POSSIBLE?

In our view, these six principles for care home physical environments offer ways to achieve safer, welcoming care homes, designed for current and prospective residents and staff in each jurisdiction and community, including in disease-outbreak conditions. Learning from research conducted since the pandemic began, as well as from the decade that preceded it, we have outlined how physical environments are adapting to increased infection control and its impact on resident and staff comfort and safety. Rather than dealing with infection control as a stand-alone issue, we have incorporated these considerations into principles that focus on the conditions of living and working in care homes. Care homes continue to hold the potential to provide safer, dignified living and dying for those who need continuous medical and social care. Physical environments are one important key to ensuring they achieve it.
REFERENCES


7. Family members and nursing home care: lessons from Ontario and Sweden during Covid-19

Ruth Lowndes, Jacqueline Choiniere, and Petra Ulmanen

We did not have an opportunity to talk to our loved ones to explain what the situation was, why … we were no longer going in. And I remember going and trying to see my husband at the window and just crying my eyes out … We were locked out for 3 1/2 months. (Wife, Ontario)

Suddenly and unexpectedly banned from visiting nursing homes during the Covid-19 pandemic, families in many countries could only wonder and worry about their relatives: Were they okay? Had they contracted Covid? Were other residents or staff infected? Were they getting the care they needed? Families lived in fear of the worst during those first months of the global pandemic while they waited to get back in.

Covid-19 severely impacted residents of nursing homes, a particularly frail and vulnerable population, and quickly accentuated pre-existing structural issues in nursing home care. In this chapter we examine similarities and differences in family members’ engagement in nursing home care in Ontario, Canada and in Sweden during the Covid-19 global pandemic. Our intent is to surface the strengths and weaknesses in the jurisdictional responses, in order to better prepare nursing homes for a more promising approach in future pandemics.

Families are often involved in their elderly relative’s care, both before and after placement into a nursing home (Gladstone, Dupuis, & Wexler, 2006; Høgsnes et al., 2016). In both Ontario and Sweden, engagement in their relative’s care often continues with regularly visiting the nursing home, providing social and emotional support, and overseeing care provision, among other care-related activities (Gladstone et al., 2006; Holmberg, Hellström, & Österlind, 2020; Turcotte & Sawaya, 2015; Wallerstedt et al., 2018). Despite the general and supportive engagement of family members in the two countries, there are differences in the degree and particularities of their
involvement. In Canada in 2012, 5.4 million people provided care to seniors aged 65 years and older, 14 percent of whom helped a senior living in a care facility (Turcotte & Sawaya, 2015). Of all the family carers assisting relatives in a facility, 22 percent were doing this more than ten hours a week and were most likely providing personal care (Turcotte & Sawaya, 2015). In Sweden, while families remain engaged, their caregiving work is less extensive and less likely to include daily personal care activities (Holmberg et al., 2020; Ulmanen, Lowndes, & Choiniere, 2023).

Sweden and Canada represent two social policy approaches in relation to nursing home care: a universal, social democratic one in Sweden, with a comparatively generous provision of tax-funded care services for all social groups (Chapter 1), and a more selective, liberal approach in Canada, with less generous public funding and where the individual’s or family’s financial situation determines access to important aspects of care (such as having a private room, or additional services) (MacDonald, 2015). In a previous work (Ulmanen, Lowndes, & Choiniere, 2023), we compared the amount and type of unpaid care by families trying to navigate the long-term care (LTC) system in Ontario, Canada and Sweden. Our intent was to assess if and how Sweden’s more social democratic, universal approach led to different family experiences than Ontario’s more liberal approach (MacDonald, 2015; Vabø & Szebehely, 2012). While we did find important differences (Ulmanen, Lowndes, & Choiniere, 2023), it is significant that our data were collected prior to Covid-19.

Given the pandemic’s devastating impact on nursing homes in particular, we revisit this comparison, focusing on the similarities and differences between the two jurisdictions and their influences on how family members experience their relationships with the nursing homes when a global pandemic strikes. For example, in both jurisdictions, families were banned from visiting their relatives in nursing homes and their communication with the home changed significantly. A devaluing of family members’ knowledge and skills regarding their relative’s care was a long-standing concern (Barken, Daly, & Armstrong, 2016), made even more visible during the pandemic. Our intent is to explore the disconnect between family engagement in care, and their lack of inclusion in decision-making and policies around that care, within the context of Covid-19.

Our analysis relies on data focused on interrelationships between staff, families, and residents from Sweden and Ontario. The perspectives of all three groups are important where family involvement is concerned, since together they paint a picture of differences and similarities across and between the two jurisdictions. Specifically, we base our analysis on interviews with 15 family members in Ontario, Canada conducted between February and March 2021, approximately one year after the pandemic started. The Ontario family
members, all of whom were involved at some level in family councils across the province, included two nieces, seven daughters, four wives, one son, and one sister of relatives in nursing home care. For Sweden, our analysis is grounded in two interview studies. The first includes 21 family members with relatives in two nursing homes (one in Stockholm and one in another municipality) prior to Covid-19. In the second study, 21 care staff (four managers, four registered nurses [RNs], eight assistant nurses, three care workers employed by the hour, and two care workers working night shifts) from four Stockholm nursing homes participated at the end of the fourth Covid-19 wave between February and March 2022. Our analysis of the interviews in Ontario and Sweden revealed three prevalent themes: access, communication, and advocacy.

ACCESS

On March 9, 2020, the first Canadian death related to Covid-19 was recorded (Grant, Woo, & Weeks, 2020). The elderly gentleman lived in a Vancouver, British Columbia nursing home and was among the first few people infected during the initial outbreak (Grant, Woo, & Weeks, 2020). Early in the pandemic, seniors were deemed at highest risk both for becoming infected and for suffering poor outcomes. Not long after this first death, Covid swept across Canada and spread rapidly through nursing homes. Ontario alone had 16 nursing homes, out of a total of 627 (Canadian Institute for Health Information, 2021a), with outbreaks by March 26, 2020 (Grant, 2020). On March 29, nine residents died, and 34 staff members were infected with the coronavirus (Grant & Mahoney, 2020). “During the first wave of the pandemic, 37% of LTC residents infected with COVID-19 in Canada died from the virus, accounting for 6,080 deaths” (Canadian Institute for Health Information, 2021b, p. 9). Ontario and Quebec had proportionally the highest number of outbreaks involving resident cases, with 34 percent of Ontario homes affected (Canadian Institute for Health Information, 2021b).

On March 14, 2020, the Ontario Chief Medical Officer of Health issued a memo recommending all provincial nursing home visits be banned, except for one family member of gravely ill residents who were close to death (Rocca, 2020). Due to the speed of the disease process and lack of communication, this left many families suffering the loss of their loved ones without being able to say goodbye. Moreover, family members who had, until this point, been going in sometimes every day and many times a day to provide care and to support their relative, were no longer able to see or talk to them, or get information on their status. This ban, implemented as an attempt to stop the spread of disease, proved detrimental to the health and well-being of families and residents alike. The ban was in place for several months until the Ministry of Health and
Care homes in a turbulent era

Long-term Care (MOHLTC) allowed for designated “essential caregivers” to enter homes.

In Sweden, on March 11, 2020, the first related death was confirmed (Swedish Government Official Report, 2020), the same day Covid-19 was reported as a pandemic by the World Health Organization. By March 22, 2020, 13 people had died of Covid-19 in Swedish nursing homes (National Board of Health and Welfare, 2022). The Stockholm region was most severely hit by the first wave and had the highest nursing home death rates in the country (Swedish Government Official Report, 2020). In an April 2020 survey, infections were reported in 510 out of 2,040 nursing homes in the country. In the Stockholm region, two-thirds of nursing homes had infected residents, compared to 18 percent in the rest of Sweden (Edwinsson, 2020). By mid-July 2020, “7.0 per cent of care home residents in the Stockholm region had died of COVID-19 compared to 2.2 per cent of the care home residents in the rest of the country” (Szebehely, 2020, p. 8).

Several municipalities, including Stockholm, and private providers implemented a nursing home visiting ban in March 2020, similar to the one in Ontario. A national ban was implemented on April 1, 2020 and lasted until October 1, 2020. Also similar to Ontario, nursing homes could make exceptions for residents’ family members to visit in the final days of life, but they did not always make this exception. In Sweden, too, many residents died without a family member by their side. An added similarity is that authorities’ instructions to nursing homes were often late and changed repeatedly (Swedish Government Official Report, 2020, 2021).

In contrast to Ontario, a ban on visits was criticized as a severe limitation of individual rights, because residents in Swedish nursing homes rent apartments, which are legally regarded as their own home. The national ban was also criticized for being imposed too late to limit the spread of disease, and applied for too long, given the negative consequences on resident and family well-being (Swedish Government Official Report, 2020), resulting in its removal prior to the second wave (National Board of Health and Welfare, 2020). After the national ban was lifted, there was no legal support to ban visits. At the onset of the second wave, some nursing homes started once again to ban visits. A new regulation came into force, mandating municipalities to request temporary permission to ban nursing home visits. On June 1, 2021, this regulation was repealed, with one reason being that “a visiting ban restricts people’s constitutionally protected rights, which could lead to increased risks of mental and physical illness” (Health and Social Care Inspectorate, 2021, p. 16).

In Ontario, residents’ families had heart-wrenching stories of how they worried about their relatives, often not knowing whether they were okay, or even alive. Residents were required to remain in their bedrooms for long periods of time. As one family member told us, her dad “was held a prisoner
in his room for seven weeks. No showers. No getting out.” Another explained that resident stimulation was extremely low during Covid-19, with people left in bed for entire days due to staff shortages. Staffing levels, already critically low (Harrington & Jacobsen, 2020; Lowndes & Struthers, 2016), were severely impacted as many homes found themselves extremely short-staffed due to illness and high turnover (Grant & Stone, 2020). Some contracted the illness or had to isolate for two-week periods due to exposure, and others left the sector out of fear. Importantly, the MOHLTC mandated employees work in only one facility to contain disease spread. Prior to Covid-19, many homes had employed casual and part-time workers as a cost-saving measure. Staff, unable to acquire full-time positions, had traditionally worked in two or more homes in order to cobble together a decent living wage. With the implementation of the new one-facility policy, many nursing homes, already challenged with reduced staffing ratios, experienced even greater shortages. And the workers, forced to choose one home, faced great difficulty in making ends meet. A family member described how her aunt’s home was “totally overwhelmed” with the loss of staff: she emailed a radio station for outside help when they announced a task force was being set up. She received a response from the doctor who had spoken on the radio, telling her they would make an appointment and go in.

[Help] didn’t come exactly the way we wanted it in a sense because it was almost like a SWAT team. They came in. They assessed all the residents. They did certain things and then they went on to another home and they … would leave maybe a couple of people there on-site, but they weren’t maybe able to fill all the staffing gaps that were there. Because by then the rule had come out that you could only work in one home and our home didn’t offer the workers as many hours as other homes. So, a lot of the regular workers went elsewhere.

In the Stockholm nursing homes, managers and staff told us about their fear of catching Covid-19 or giving it to residents. They were short-staffed because of illness, and those afraid of becoming ill called in sick. Infected residents were isolated, which demanded extra staff, often on a one-to-one basis: these workers were prevented from engaging with other residents or staff. Later on, infected residents were moved to specific Covid units and these workers were not to go into any other unit. With staff shortages, the increased workload, and measures taken to limit virus spread, resident stimulation decreased.

Although Sweden has higher nursing home staffing levels (Organisation for Economic Co-operation and Development, 2021), both Sweden and Ontario rely heavily on casual and part-time workers (Armstrong & Szebehely, 2023). In Sweden, there was no national mandate for employees to work in only one facility to contain disease spread. Instead, municipalities like Stockholm used other strategies to achieve this goal. At the beginning of the pandemic, the
Stockholm municipality instructed and provided funds for homes to increase staffing levels. Since hiring new staff increased the risk of disease spread, the primary strategy was to increase work hours among existing staff. Those employed by the hour were offered more hours or temporary full-time employment (Stålö et al., 2021).

While staff at the Swedish sites put in many extra hours, it was not enough, and managers endeavoured to quickly find extra staff. Nursing homes tried to avoid having staff going between units, or working in other homes, but were not always successful. A manager told us that since hourly workers, normally working part time, were offered so many hours, she did not believe they needed to work elsewhere. Two managers reported that money was not a problem when staffing the home. If Covid-19 came into a unit, they hired staff to provide cohort care without hesitation, but finding qualified staff was problematic and so was accessing personal protective equipment (PPE). A Swedish RN told us: “All of a sudden there was money for everything. There was no personal protective equipment, but there was extra staff to provide cohort care.” Lack of PPE and limited access to testing was a similarity in both jurisdictions (Marrocco, Coke, & Kitts, 2021; Swedish Government Official Report, 2020, 2021), with Ontario and Swedish nursing homes given much lower priority than hospitals despite the elderly being susceptible to poor Covid-19 outcomes.

In Ontario, the pandemic also increased the concern and guilt of family members, who were left wondering if they had made the right decision to place their relative in a nursing home. The remorse that family members described about placement is likely related to the notion that a nursing home is the last resort, and the result of failure to care for their relative (Armstrong et al., 2009), and the significant guilt arising from that assumption (Um, Sathiyamoorthy, & Roche, 2021). A sister expressed the extreme guilt she felt for deciding to move her brother during the pandemic when she could not visit or gather information on his health and well-being:

My worst nightmare, the guilt when he went into long-term care and I’m still really, really feeling guilt. Within three weeks he got Covid. He hates it there. He wants out. Unfortunately, he has dementia and unfortunately he still can reason. He’s not in the final stages of dementia. So almost every day [he told me to] get him the hell out of there … And I was just in panic mode all the time … I wasn’t allowed in … I just felt so guilty because as his power of attorney, right, I let it all happen.

This relative already felt culpable for making the decision to place her brother in a nursing home, and the policy restricting visits during the pandemic meant that she had to drop him off at the front door and leave. He contracted Covid, worsening her sense of guilt. Adding further anguish, during the first wave of Covid, Ontario families were urged by, among others, a geriatrician, to
Family members and nursing home care

105

take their relatives from nursing homes and care for them at home (Picard, 2020). This increased pressure on family members, as described by a daughter who has a mother in a nursing home: “[I]n one of my last conversations with a media person, he said, ‘Well, why don’t you take your mother out?’ I said, ‘We thought about it but it’s not the right thing to do.’” Family members need to feel good about placing their relative in a nursing home and know they will be adequately cared for. In Ontario, families often attempt to fill in care gaps to ensure their relative’s needs are being met, as expressed in the following comment by a relative of a deceased aunt:

[I] wish in retrospect that I’d had more time for just sitting, socializing because frequently there were just so many things to do that I actually felt that I was doing those things instead of just sitting down and talking. But long-term care in my experience, not just my own experience but my experience of other families that I’ve talked to, it requires a lot of work from the family caregiver, trying to make sure that everything is good.

Our study of family members prior to Covid-19 indicated that, in comparison to Ontario, Swedish families did not experience the same level of guilt (Ulmanen, Lowndes, & Choiniere, 2023). Most Swedish family members described their relative’s admission as positive, offering a sense of relief after enduring many short visits by multiple homecare workers and frequent hospital admissions. Family care responsibilities were willingly relinquished because there was continuity of care and increased safety with nursing home staff being present 24/7. Families explained their relative was no longer alone for long time periods, and if something happened, they received help quickly, easing the families’ worries. Although most recognized improvements were required, they trusted staff and did not feel the need for advocacy (Ulmanen, Lowndes, & Choiniere, 2023).

Swedish staff described family members as feeling worried but not guilty about their relative’s well-being during the pandemic. While they did not mention any resident moving back home or even discussed it as an alternative, fewer people were moving into nursing homes than before the pandemic. In Sweden, in 2020, there was a marked decline in the number of senior citizens moving into nursing homes, as many older adults chose to postpone this move. There was also a decline in those seeking homecare. In 2021, the number moving into nursing homes increased, yet those who chose to cancel their homecare continued to increase (Swedish Government Official Report, 2022). To postpone the move to a nursing home and receive homecare instead would not necessarily protect against the infection, since these individuals required homecare several times a day and received it from multiple homecare workers. Indeed, by the end of 2020, of seniors 70 years or older who died from Covid-19, half lived in a nursing home and almost 30 percent were
receiving homecare (Swedish Government Official Report, 2020). According to a Swedish survey, family members’ fear of catching COVID-19 made them hesitant about letting their relative use care services, and in some cases they refrained from homecare or nursing home care (Magnusson et al., 2021).

COMMUNICATION

In Ontario, severe staffing shortages created enormous communication issues. Most family members across our study described their inability to reach anyone by telephone or email for long periods of time. A sister whose brother was admitted to a nursing home at the beginning of the pandemic lamented the lack of communication:

It was non-existent. When he had Covid it was totally non-existent … I called about 30 … times in a month without ever getting through at all. I got through five or six times but half of them I had to leave a message. I heard from the doctor once in all of that period.

Other family members shared similar stories of their inability to obtain information about their relatives’ health and well-being.

So, communication was always an issue. And then with Covid coming along it became a huge issue because you were scrambling for any little bit of information. You couldn’t get anybody to answer the phone … We were away when the world flipped in Ontario. So, we came back to quarantine. I had a cousin call me to tell me that they had heard on the news that there was an outbreak at [name of nursing home]. (Daughter, Ontario)

Communication was a common complaint among Canadian families, even prior to Covid-19, a concern our team has discussed (Barken & Armstrong, 2020). The pandemic brought this issue to the forefront. Our study of residents’ family members in Swedish nursing homes prior to the pandemic offers a clear contrast. Most family members reported that communication with staff worked well. As we’ve argued elsewhere (Lowndes et al., 2023), Swedish nursing homes, due to higher staffing levels and their system of key contact persons, offer staff opportunities for better communication and relationship-building with families.

Swedish nursing home staff reported that responding to worried family members’ questions during the pandemic, while important, was time-consuming and increased workload. In one of the homes an RN dedicated to this role said, “Many days we had one RN … who only answered telephone calls from family members.” To reduce the number of calls, several homes sent families weekly email updates. In the early stages when little was known about the
speed and severity of Covid-19, staff were unable to inform families quickly enough of their relative’s status. In several cases, the resident died the day after families were informed that they had contracted Covid. Therefore, they were not always able to visit before their relative died. A manager described family members’ reactions, including reporting the nursing home to the Health and Social Care Inspectorate: “We did everything we could … But many family members, a couple of them … [with relatives who] died very quickly, were very … dissatisfied.”

Also in the Sweden sites, physicians refrained from visiting nursing homes during the pandemic and instead made assessments online or by telephone, which led to communication problems. Physicians were making decisions to keep residents in the home, without first examining them. This, coupled with regulations issued by Region Stockholm indicating that most residents should not be prioritized for hospital care, led to a marked reduction in residents being transferred to hospital (Swedish Government Official Report, 2020). Stockholm staff told us about family members who questioned how the physician could decide that residents should not go to hospital without first seeing them. Staff reported that some family members called the emergency number themselves to have their relative transferred to hospital. Staff were caught in the middle, as an RN described:

But it was hard for family members to understand … We got many calls, sort of “how can you decide that my father … cannot go to hospital although no physician has even met” … Then we were standing in between, okay, what are we going to say. The physicians will not get here, but family members want a physician to meet their relative to decide. It’s not an easy decision to make, that it is palliative care.

The RN told us that families filed complaints to the Health and Social Care Inspectorate several times, reporting that they had not received enough information on their relative’s health status: reports also concerned physicians who had decided not to send a resident to hospital.

ADVOCACY

During the first wave of Covid-19 in Ontario, with access denied and communication lacking, family members often turned to family councils to gather whatever information they could about their relative and about the home, as described by one family council member.

Now, the families became a very cohesive group. My family council … doubled in size. And it wasn’t because everybody had time. It was because everybody needed the information. And we became like a network of intense communication … And any little tidbit of information we could get was passed along by email to families
who are now part of the family council, the enlarged family council. And we just did our best to inform one another.

Family members pulled together during this very stressful time and advocated for numerous things, including information on resident status, re-entry into nursing homes, and policy clarification on, for example, the “essential caregiver.” In Ontario, the MOHLTC developed directives on Covid-19 management measures, which nursing homes were mandated to follow. Directive #3 outlined, among other items, the visitor policy: “essential caregivers” were deemed to be “performing essential support services” (Ministry of Health and Long-Term Care, 2020). A daughter offered an example of the types of misinterpretation that were occurring around this directive.

[I had a] huge battle with the nursing home over Directive #3 and what it meant. They put up so many roadblocks for my sister to do the paperwork on declaring her and myself to be the essential caregivers and what that meant. And no we couldn’t go in, and they could [bring dad] downstairs to the lobby, and only at certain times, and if you booked six weeks in advance. Just roadblock after roadblock … I think for their benefit to try and control Covid but forgetting that these are human beings there and they need to see their family and their family needs to see them.

A daughter whose mother was in a nursing home explained they formed a family council of three people and advocated to get back into the home.

Ironically, the way we got back in there … when we weren’t getting back in and we weren’t getting the essential caregiver policy provided to us … as chair of the family council, [I] went over [name]’s head and went to [for-profit company], to some head honcho at [for-profit company], and said, “This is unacceptable. This is terrible. We’re not happy and we need to get back in there” ... And then it was very shortly after that we got the word that we were going back in. So, it did have an impact.

A niece whose aunt died of Covid-19 echoed the struggles associated with trying to figure out how to advocate and navigate within the LTC system effectively and collectively.

[M]ore and more, especially after Covid started, there was a lot of times trying to understand the government structure, the Ministry, who’s responsible for what. And even in terms of the ownership of the home, we got a lot more involved. Not just myself, but the whole family council, trying to understand, if we can’t get action in the home, where’s the appropriate place to go outside the home. Because the home was owned by one company, operated by another company and so who do you go to? The operator? The owner? Do you go to the Ministry? Do you go to the patient Ombudsman? What’s the most appropriate place to go?
In Ontario, families came together through family council membership to navigate a confusing system to gather information, to clarify policies enabling re-entrance, to advocate for all residents, and to build networking systems with other nursing homes. Family councils grew and became an important networking pathway for Ontario family members.

In Sweden, prior to the pandemic, family councils were not described by families as a crucial channel for communication or advocacy, maybe because families were generally satisfied with nursing home care and felt they could discuss concerns with staff and leadership directly. Additionally, although staff talked a lot about families and their concerns during Covid-19, and about the time-consuming communication efforts, they did not mention family councils. Instead, they told us family members advocated individually for information on their relative’s health status, to be allowed to visit, and for their relative to be assessed by a physician and/or sent to hospital. Another Swedish study of family members confirms they had complaints during the pandemic, especially regarding the absence of information or getting unclear or inadequate information (Magnusson et al., 2021).

FAMILY RECOMMENDATIONS TO IMPROVE CARE QUALITY

Ontario families offered suggestions for future changes. They highlighted the importance of having enough trained staff with satisfactory remuneration so that families could choose, if they wished, simply to visit their relative instead of having to provide hands-on care out of necessity. Aptly put by one family member, “[I]f they have enough staff, why do I have to go in to ensure that my mother is being fed? Why do I have to ensure that she’s clean? Why can’t we just go in to visit?” A wife echoed this sentiment, “Did I want to go in and start over again what I was doing at home? Absolutely not. Not in a loving way because … his personal integrity didn’t care for me helping with his personal hygiene.”

Our study of family members in Swedish nursing homes prior to the pandemic provides a clear contrast to these experiences in Ontario. Family members did, in fact, perceive themselves as visitors, not unpaid care providers, and they were happy about this. Several family members also thought their relationship with their relative had improved after the move to the nursing home. Adult children explained how much nicer it was to visit their parent in the nursing home than in the parent’s home, because they could sit down and spend time together, instead of running around doing all that needed to be done.

The importance of focusing on residents’ emotional well-being was emphasized in both jurisdictions. Ontario families stressed that staff do not have
time to engage relationally with residents, a concern our team has written about extensively (Armstrong & Braedley, 2013). A wife reiterated our team’s recommendations: “they need to hire enough people [so] that people can sit with somebody and stimulate them, talk with them one-on-one, have time to do that.” To do this, there needs to be more staff with full-time opportunities to assist with care continuity and relationship-building among staff, residents, and families. Given higher staffing levels and an emphasis on social care, Swedish nursing home staff have more time to engage relationally with residents than staff in Ontario. Even in Sweden, family members wished for more social interaction to improve the care provided. In addition to more time for staff to interact with residents, they asked for others such as students and professional groups like deacons⁶ and psychotherapists to come into the home and engage with residents.

Ontario families expressed the desire to be a part of a team involved with decision-making, to ensure homes have policies and processes that support quality care, and to be recognized for their expertise. In short, families wish for meaningful and rewarding inclusion.

I know that there are many, many residents in there who either don’t have family or who don’t have family that care. But there are lot of us who do care. And there’s no opportunity … to be part of the team. We’re always the outsiders. We’re always looked down upon. We’re a nuisance. We’re a bother … There has to be a better way of getting families involved from day one. (Wife, Ontario)

Families also called for better, consistent communication policies for nursing homes. “Teach them how to communicate. Crucial. Crucial. Crucial” (Wife, Ontario). The pandemic shed light on the poor communication between nursing homes and families, which has been an ongoing concern in Ontario. Families were left in the dark during the first wave, unable to enter the home or receive updates. Family councils became important sources of information and were families’ support systems during a very stressful time. A new family council was formed in one of the homes, while other councils grew in numbers, and collectively they were used to gain entrance into homes, to communicate with administration on directive interpretations, and to create policy changes. As an effective communication strategy, a mandate to ensure all homes have a successful, functioning family council may be of benefit in the Ontario context.

Swedish staff did not describe family councils evolving in the same manner during the pandemic, or communication breaking down like it did in the Ontario homes. The higher staffing levels and the contact person system in Swedish nursing homes may have contributed to families feeling as well-informed as possible, under the circumstances. These conditions proba-
Family members and nursing home care

bly generate a higher level of trust towards nursing home staff, which eases communication in case of a major crisis such as the pandemic.

Most [families] appreciated that we worked, many came and said that you were heroes, that we did not dare to come and visit our parents but you were out there working. Most of them were very grateful and understood why they were not allowed to come … It’s only positive when family members come, I’m talking about in ordinary cases. They are helpful, they ease our work. They are the ones who know the residents more and they explain. (RN, Sweden)

Family members’ appreciation and trust is evident in this RN’s description, as is their important contribution of resident information.

In summary, Covid-19 has brought to the forefront issues in nursing home care that our research has been documenting for over a decade. Focusing on access, communication, and advocacy during the pandemic, this chapter makes visible the impact that pre-existing structural conditions have on family member inclusion in the care of relatives in nursing homes. In the Ontario context, long-standing inadequate staffing levels gravely impact resident, family, and staff health and well-being. Already critically low, staffing levels plummeted during Covid-19, due to isolation mandates, along with staff exiting the sector for fear of contracting the illness, leaving residents in dire situations. The government policy requiring employees to work in only one location further contributed to reducing staffing ratios. In Sweden, there were no national policies negatively impacting staffing ratios; employees could work in more than one home. Moreover, despite the higher staffing levels in Sweden, some municipalities made additional human resource funds available at the beginning of the pandemic. A well-documented recommendation states that Ontario should increase staffing levels to at least 4.5 hours worked per resident per day, given the increased complexity of resident needs (Schnelle et al., 2004).

Government policies in both jurisdictions that were intended to stop disease spread had grave impacts on family member inclusion. In Ontario, the ban on visitors left families, who often filled in care gaps, waiting helplessly on the outside, fearing the unknown. The focus on disease management in our biomedical care model also brought to light the extreme lack of emphasis on social well-being during Covid-19. Ontario families, who often provide social care when visiting, were unable to do so during the pandemic, sharing tragic stories of their relatives being in bedrooms for weeks on end, not even able to go outside for fresh air. Although Sweden also had the visitor ban in place, their social care model contributed to its removal, as it was deemed to be discordant with constitutional rights. The argument in Sweden was that these are residents’ homes and as such, families could not be banned. In contrast to Ontario, Swedish families do not typically provide day-to-day care.
such as assisting with eating or bathing, and so this concern did not surface. Even though Sweden has a social care model, an increased focus on disease management during the pandemic also negatively impacted social well-being of residents and families.

Communication issues between nursing homes and families, a long-standing concern across Ontario’s LTC system, worsened considerably during Covid-19. Families were often unable to gather any information regarding their relatives, the home’s status related to disease outbreaks, or new government policies that would facilitate their access into the home. One positive outcome from the poor or “non-existent” communication between families and homes was the growth of family councils, which became important advocacy networks, supporting families through information sharing, deciphering MOHLTC policies, and advocating for change. In the Swedish homes, although information was at times not available because of the nature of the disease, it was much easier than in Ontario to reach staff to inquire about their relative’s status. The Swedish key contact person model, a positive structural strategy that ensures consistent connections between staff and family, likely contributed to better communication overall during the pandemic. It is an approach that would be beneficial for care quality in Ontario.

In both jurisdictions, moving forward, families must be involved in policies that direct resident care, or if they choose to not be involved, be confident that their relatives are receiving quality care. Their expertise regarding residents’ backgrounds and particularities, often invisible, must be recognized as critical to care quality. Families also need to be involved in ways that are meaningful and rewarding for them and their relatives. Families should not be expected to make up for inadequate staffing levels, but rather be there for social support. This requires enough staff to engage relationally with residents and families, rendering social care integral to nursing home care. Families can then begin to trust that the long-term care system has the necessary resources to provide all aspects of care, and that their relative is safe and has a good quality of life.

NOTES

1. The Ontario, Canada “COVID-19, Families and Long-term Residential Care” is funded by Social Science and Humanities Research Council of Canada and led by Dr. Pat Armstrong.

2. In Sweden, employment by the hour implies a non-permanent position, with when and how much the person will work decided on a day-to-day basis. Following OECD definitions (2020, p. 31), it corresponds to both casual employment, which does “not have regular or systematic hours of work or an expectation of continuing work” and a zero-hours contract, “in which the employer is not obliged to provide any minimum working hours.”
3. The Swedish project, “The Staff’s Experiences of How the COVID Pandemic was Handled in Nursing Homes,” is funded by the Center for Business and Policy Studies, with principal investigators S. Erlandsson and P. Ulmanen.

4. Cohort care refers to staff working strictly with ill or well residents and/or grouping together residents who are ill, strategies meant to reduce spread of infection (Public Health Ontario, 2022).

5. Each resident has a contact person who spends an hour per week focusing on their well-being and keeping in touch with their family (Szebehely, 2016).

6. In Sweden, a deacon is employed by the church to provide personal support or counselling, similar to a social worker, not necessarily focusing on faith but on any personal matter.

REFERENCES


8. Equity and diversity in nursing home care: lessons from Canada and Sweden

Prince Owusu, Susan Braedley, and Palle Storm

Anti-racist and queer activists and advocates have raised concerns about the failure of nursing homes to provide safe, respectful conditions for residents, families, and staff who are Indigenous, racialized, immigrants, members of 2SLGBTQIA+ (two-spirit, lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual, and additional sexual orientations and gender identities) communities, and from religious, linguistic, and cultural minority groups. Despite the flurry of public attention to nursing home problems since the onset of the pandemic, this critique has received little media coverage or policy attention. Yet failures to address diversity issues are eroding the quality of work and care in nursing homes, for many reasons. First, despite significant global migration to high-income countries, these jurisdictions have done little to consider how best to support immigrants as they age (Braedley et al., 2018; Koehn et al., 2018). Second, immigrants are increasingly recruited to fill care labour shortages, yet most nursing homes have not addressed xenophobia in the workplace. Racialized women and some men form a significant proportion of the nursing home labour force, but policy and practice have lagged in addressing systemic racism (Syed, 2020). Public policy shifts to recognize sexual and gender diversity have had little impact on nursing homes, despite homophobic and transphobic practices that require many 2SLGBTQIA+ residents to closet their sexuality and gender identity to access care (Brotman et al., 2015). Workers are similarly affected (Streeter et al., 2020). Perhaps most significantly, nursing homes are profoundly gendered institutions in which both residents and staff are overwhelmingly women, and questions of how to address diversity are always also questions of gender equity.

In this chapter, we envision a future for nursing homes as collaborative, culturally diverse, equitable organizations with deep, daily connections to the communities outside their doors. We work to imagine how nursing homes can support the needs, cultures, and values of diverse groups of residents and staff.
Care homes in a turbulent era

in ways that both affirm these community members and ensure equitable treatment. To do so, we explore and compare nursing home policy and practices in Canada and Sweden: two countries with significant, growing population diversity and commitments to multiculturalism and social inclusion.

We begin with a brief overview of the complex social policy contexts that shape nursing home care in these countries. We discuss the need for nursing homes to respond to population diversity and some of the barriers to change. Drawing on relevant data from empirical research with nursing home residents, family members, and staff, we point to the contradictions and tensions inherent in addressing equity and diversity concerns. We conclude by offering promising examples of approaches to equitable care.

COMPARING SOCIAL POLICY CONTEXTS

Significant to issues of population diversity and social welfare, Canada’s liberal welfare regime and Sweden’s social democratic one (Esping-Andersen, 1990) share a similar multicultural approach to citizenship, adopted in both jurisdictions during the 1970s (Matveevskaya, et al., 2021). Stated simply, multiculturalism signals integration without assimilation and is based on principles of recognition and inclusion. However, these countries differ in their social welfare spending relative to GDP. In 2019, Canada’s social spending was 17.3 percent of GDP (Béland et al., 2021), well below Sweden’s 27.7 percent in the same year (Statistics Sweden, 2022). Canada has more universal benefit programs and services than some other liberal welfare states, but not as many as Sweden. However, some of Sweden’s welfare programs operate with a residual approach, with benefits available only to those who have exhausted alternatives in their family and on the market. Overall, Sweden’s welfare regime has taken a more universal approach to structuring and ordering its society and welfare state than Canada, with a focus on the public organization of services “that have the same content for all” (Blomqvist & Palme, 2020, p. 116), including those with higher incomes (Anttonen, 2002, p. 77).

Gender equity is more central to welfare state developments in Sweden than in Canada, with explicit aims to ensure women’s labour market and political participation. These policies have had results. In Sweden, women are paid 93.7 percent of men’s wages overall, while in Canada, women are paid 84.9 percent of men’s wages (OECD, 2022). In a Global Gender Gap Index that assesses gender equality in terms of health, income and wealth, labour market participation, education and more, Sweden ranks 5th in the world, while Canada ranks 28th (World Economic Forum, 2022).

The politics of culture and language have a long history in Canada. In 1867, the Canadian federal system was embedded in the Constitution, shaped in part to address demands by Francophone Quebec to maintain control over its...
distinctive society, language, and culture. As a result, Canadian provinces and territories have significant constitutional control over many but not all social programs, including publicly funded nursing homes. Canada is a colonial settler state, created through violent disposessions of Indigenous lands and the removal and relocations of Indigenous peoples. For over a century, Canadian policy aimed to assimilate Indigenous people, resulting in cultural genocide, significant linguistic and cultural losses, and intergenerational traumas that destroyed families and communities (Shewell, 2004). Canadian social welfare for Indigenous people varies, depending on both “Indian status” and place of residence in a contentious hodgepodge of federal, provincial, and community provision that arguably perpetuates colonial rule (Coulthard, 2014). Indigenous communities have also pointed to the explicit and implicit colonial dimensions of many governmental multicultural initiatives (Hogarth & Fletcher, 2018). A series of federal initiatives towards Truth and Reconciliation have produced many recommendations to address this long, ongoing history of inequities.

As a settler nation, immigration to Canada has always been central to both nation-building and labour supply. The Canadian “points” immigration system, admitting immigrants based on labour market-related factors such as age, education, wealth, and language proficiency rather than country of origin, has been used as a model internationally. A relatively generous family reunification program has allowed some migration of older people to Canada (Braedley, Côté-Boucher & Przednowek, 2021). The result is that the populations of Canadian cities are among the most diverse in the world. In 2019, immigrants accounted for 47 percent of the population in Toronto (City of Toronto, 2019), 34 percent in Montreal (Council of Europe, 2019), and 42.5 percent in Vancouver (NewToBC, 2018).

The Swedish welfare state has been based on “centralism and universalism, social intervention and consensus” (Rothstein, 1998, quoted in Dahlstedt & Vesterberg, 2017, p. 233), although these principles have been wobbling under decades of neoliberal incursions. Inclusion has been the primary operating principle for addressing cultural diversity in Sweden, but its form has been one that implicitly preserves Swedish values and culture (Dahlstedt & Vesterberg, 2017). That said, it has a relatively generous labour market-oriented immigration regime (Castles, 2017), and, like Canada, has made a number of policy moves to recognize diversity for both Indigenous people and some regional ethnic and linguistic minorities. For example, the Indigenous Sami people are one of Sweden’s official national minorities, and a Sami Truth Commission was established in 2021 to investigate the history of their forced removal from lands and persecution. The proportion of immigrants in Sweden is growing rapidly, although not as quickly as in Canada. In 2022, Stockholm’s population included 27 percent immigrants (World Population Review, 2022b), Malmö
had 33 percent (Malmö City, 2022), and Gothenburg had about 25 percent (World Population Review, 2022a).

Canada and Sweden recruit significant numbers of immigrant and racialized care workers into their care economy to meet care needs, including in the nursing home sector, where these women and some men make up a significant and growing proportion of the labour force (Storm & Lowndes, 2021). Laws in each jurisdiction protect workers against discrimination and harassment in employment. In Canada, these laws are embedded in provincial and federal Human Rights Codes. In Sweden, the Discrimination Act protects workers against discrimination on the basis of gender, gender identity or expression, ethnic origin, religion or belief, disability, sexual orientation, and age. These protections against harm do not specify the conditions that offer safety for these workers, however.

Finally, both Canada and Sweden have relatively strong protections for 2SLGBTQIA+ (Canada) or HBTQ (in Sweden, homosexual, bisexual, transgendered, queer) rights. According to an OECD report, in 2019 Canada had stronger legal protections than any other OECD country. Although the same report indicates that Sweden had fallen to 14th place, it performed well in protecting HBTQ individuals against discrimination and violence, and on inclusion for same-sex couples (OECD, 2020).

This overview of the social policy contexts shaping nursing home responses to diversity and equity concerns in Sweden and Canada shows that both countries have strong immigration programs, and have made similar commitments to multiculturalism. Sweden’s more universal approach to social welfare has strong commitments to equity that foreground social class, income, and gender, but do not directly address culture or sexuality. Canada’s mix of universal and residual programs has a lower commitment to equity, but Canada appears to have more public debate and advocacy around questions of diversity. These countries have different policy records on gender equity and 2SLGBTQIA+/HBTQ protections. Yet both contexts offer their respective nursing home sectors a policy environment that could support culturally safer, more equitable conditions of work and care. In both contexts, there are also policies in place that protect against discrimination and make explicit, if not always actualized or extensive, commitments to respect and dignity for Indigenous peoples, immigrants, racialized people, 2SLGBTQIA+/HBTQ people, and women.

APPROACHES TO ADDRESSING DIVERSITY IN CANADIAN AND SWEDISH NURSING HOMES

Nursing homes are an integral part of both Canadian provincial and Swedish social welfare regimes (Armstrong et al., 2009), but the policies directing
Equity and diversity in nursing home care

Nursing home care are different. Canada and Sweden make significant public investments in nursing homes (Baines & Armstrong, 2015), but Sweden’s spending as a percentage of Gross National Product (GNP) is three times higher than in Canada (Storm & Lowndes, 2021). While Canadian nursing homes generally pursue a medical model of care, Swedish care homes are guided by a social model (Szebehely, 2017), creating many differences, especially in staffing and work organization.

Swedish welfare state commitments to universalism have meant that nursing home policy aims to offer high-quality care services affordable for all social groups according to need, rather than according to an individual’s purchasing power (Simonazzi, 2009; Stranz & Szebehely, 2018). Although universalism remains an ideal in Sweden, in the case of nursing homes there has been significant erosion (Ågotnes et al., 2019). In Canada, provinces and territories set their own regulations for nursing homes and there are significant differences among these jurisdictions, making cross-national comparisons difficult. And while income is not a barrier to entry in Canada, there are some barriers to care, including long wait times and other restrictions that shift more care to families than in Sweden.

In both countries, nursing homes developed as local institutions with staff and residents generally coming from the same community. In Ontario, Canada’s most populous and most diverse province, nursing homes moved from being primarily a municipal concern to a provincially regulated and funded one in 1972, with dramatic effects on provision that included substantial efforts to address quality concerns (Baum, 1999). In Sweden, publicly accessible elder care increased with the expansion of the welfare state in the 1960s, but it was not until the 1992 “ÄDEL reform” that nursing homes became extended care settings provided by local municipalities (Storm & Lowndes, 2021). In both contexts, however, most nursing homes reflected the dominant culture of local, relatively homogeneous communities, including religious affiliation, language, history, and understandings about care work and older people.

This population homogeneity is no longer the case, for three reasons. First, global migration to Canada and Sweden means that in urban centres, and increasingly in smaller towns and rural regions, populations include significant numbers of people born in other countries as well as incomers from other regions. The older population is increasingly diverse in terms of race, religion, ethnicity, culture, and language (Koehn et al., 2018). Nursing home staff are also increasingly racialized women and some men, with high proportions of immigrants in both these jurisdictions (Storm, Braedley, & Chivers, 2017; Storm & Lowndes, 2021). In addition, politics have shifted the conditions for sexual and gender diversity, and more older people, their families, and care workers identify as part of a sexual or gender minority.
Second, many more people move in later life, not only across town but across countries and the world. Fewer nursing homes are serving “local” people who know each other. In Sweden, this effect is muted due to local control of nursing home beds in 290 designated municipalities. This means that Swedish residents receive care in their own community. In some areas of Canada, however, prospective residents must take “the next available bed,” which could be several hours’ drive from their current home. People who live in rural and remote regions in Canada are often brought to cities for care, to places hundreds or even thousands of kilometres from their residences.

Third, nursing homes in Canada and Sweden are increasingly both big business and highly regulated by the state, although there are significant differences in the degree of these changes in Sweden and across Canadian jurisdictions (Armstrong & Szebehely, 2023). Although the extent of for-profit nursing home ownership varies from jurisdiction to jurisdiction, even publicly owned nursing homes may outsource some operations such as payroll, maintenance, cleaning, laundry, and food services to for-profit companies. Both privatization and regulation tend to standardize nursing homes, producing “models” for physical structures and approaches to care that prioritize consideration of costs, risks, safety, and other managerial concerns. This tendency towards standardization is evident even in jurisdictions with a mostly publicly owned and operated nursing home system (Armstrong & Armstrong, 2020), and makes addressing diversity more challenging.

We have yet to discover any nursing home regulations that address and ensure consideration of language, culture, sexuality, and gender identity, although there are indications of change in some Canadian jurisdictions and in Sweden.

In Sweden, the welfare state vision has been of a well-developed care sector used by all social groups of older people that can advance equality of care despite differences in income or class. Care arrangements are designed to be sufficiently individualized and flexible to respond to different needs and preferences (Szebehely & Meager, 2018). An underlying assumption is that nursing home providers have the necessary competence to facilitate a range of different care needs, but the degree to which this assumption includes culture and language is less clear. All elder care services in Sweden, including nursing homes, are regulated by the Social Services Act (2001, p. 453). This legislation does not confer rights to culturally specific care services and makes no mention of ethnicity, religion, sexual orientation, or gender identity. However, in 2019, an addition to the Act required municipalities to retain staff with skills in the five Swedish minority languages – Finnish, Jiddisch, Meänkielä, Romani, Chib, and Sami – when needed (Social Services Act, 2001, p. 453). Nursing homes for specific social groups, such as Jewish, Sami, and Finnish nursing homes, have existed for a long time, but remain somewhat peripheral in the
sector. Brodin (2005) has argued that the Swedish public elder care sector is permeated by gendered and racialized power structures marked by norms of “Swedish-ness,” aligning with Siverskog (2016), who has commented on its heteronormativity. The work of these authors raises important questions about whether those whose identities and communities fall outside norms of “Swedish-ness” are able to access care services when needed.

But whether in Canada or Sweden, the challenges and complexities involved in nursing home care with heterogeneous populations are similar, as empirical research studies have shown. Mahwin Kiwi’s (2019) research with the Iranian community in Sweden illustrates some of these issues. A research participant described her experience with her father’s admission to a mainstream nursing home:

In the Swedish nursing home, they had no Persian-speaking staff, but the nursing home was very beautiful, clean, and nice. But over 24 hours, they called me at least 18 times to say that my father refused to change his diaper, or my father refused to eat, or refused to shower, or that he wanted to go home. I received phone calls from the nursing home staff about 2 or 3 in the morning and according to them (the staff), my father wanted to talk to me. When I spoke with him and asked him what it was he wanted, he said: “I do not understand what people are saying to me here.” Until we found a proper place for my father, we took him back to his home. (p. 2213)

Some immigrant communities perceive nursing homes as contrary to their cultural values and as the abandonment and exclusion of frail older people who should be included in community life and cared for by extended family. This perception is often expressed by immigrant staff, including by a nurse in Nova Scotia, Canada:

It was a shock when we first came here, like leaving parents in our home and not seeing them, not involved in any of their care. It was shocking … First, the challenge was that people are dying and nobody is with them. It was very hard for us when we first started but now we know what is here.

Nevertheless, many immigrants live in nursing homes in Canada and Sweden. As a family member in Ontario, Canada told us:

Of course my family is outraged that mom is in a nursing home. If we were in India we might have more family around her and cheap paid help too. And we would have no real option if we had trouble managing. Things are different here and physically I can’t do her care. They don’t understand.
Racialized residents of nursing homes often encounter systemic racism and exclusion or marginalization:

I am the only Black resident in this nursing home. My friend is the only [Indigenous] person. Why are we friends? Because we face the same. We are the lonely only and it isn’t always easy. (Resident, Nova Scotia, Canada)

Most nursing homes in Canada do not have capacity to serve residents in a language other than the main language of the home or to attend to cultural life that is not the dominant one (Durst & Barrass, 2014; Koehn et al., 2018). Critiques from Indigenous residents have shown that their experiences in nursing homes have often been felt as one more removal from culture and community, perpetuating colonial legacies of trauma and cultural genocide (Gionnas et al., 2021; Nelson, 2021).

Yet like Sweden, Canada has a significant number of nursing homes and nursing home units that provide culturally and linguistically specific care. These include Jewish, Italian, Chinese, Dutch, Ukrainian, Greek, Mennonite, and Indigenous nursing homes and units, Francophone homes in English-dominated areas of Canada, and Anglophone homes in Quebec. Units and homes for 2SLGBTQIA+ residents are beginning to be developed in some jurisdictions. Most culturally specific homes and units are located in cities where there is sufficient population to produce consistent need.

While some nursing homes respond to residents’ cultural and linguistic backgrounds, research with nursing home workers across Canada and Sweden has revealed obdurately “white” values and culture shaping nursing homes in both countries. Whiteness as dominance manifests itself in colour-blind ideologies that support the privileged positions of white people and subjugate racialized people (Rankin-Wright, Hylton, & Norman, 2020). Care workers, and especially immigrant care workers, are usually not considered in efforts to ensure cultural safety and access. Their experiences of racism and sexism on the job include “othering” on multiple levels, from microaggressions in mundane interactions to a systemic glass ceiling that places immigrant workers in the lowest paid positions (Behtoui et al., 2020; Dahle & Seeberg, 2013; Braedley et al., 2018).

A Black Ontario nurse discussed her experience of racist treatment from residents, her ambivalence about responding to the racism, and her co-workers’ different approach:

I’m used to it, like I know it’s not – it’s not part of who they are ... But – well my coworkers are – I find it upsets them more than it upsets me. They are like … you’re not supposed to do that and they right away correct them … come to my defence. I’m like, that’s okay, but they are like – no. That’s not accepted here. And they kind...
of correct the residents right away … I feel happy that they stand up for me but I’m like, that’s okay. I’m not. I don’t get upset because of it, but that’s okay.

In Sweden, a racialized care worker echoed this sentiment, linking her passive acceptance of racism to her sense of relative powerlessness as an immigrant:

I have experienced [racist remarks] from residents, “dirty Black” and swear words. Relatives of the resident can also remark, “How are you going to take care of her? You know nothing.” You often confront such things. We do not take it personally, the residents are sick, but the relatives ... It’s just to accept and prove you can do a good [job], then they regret it. There is nothing you can say about it. I am an immigrant.

These examples point to the “othering” of immigrant care workers in racist encounters in nursing homes. Workers are left to rationalize microaggressions without organizational support, normalizing such verbal violence. In the case of the Black Ontario nurse, their co-workers stood up for them, which is laudable, but immigrant care workers need real protections and policies that explicitly address racism on the job. In the Swedish example, a racial script of incompetence was written unto the body of the care worker and they felt obligated to prove themselves. This is an extra burden of emotional stress that racialized care workers navigate and is harmful to their psychological health (Braedley et al., 2018).

In both Sweden and Canada, nursing homes have been considered a “long-term closet” by members of 2SLGBTQIA+/HBTQ communities (Brotman et al., 2015; Chaze et al., 2019; Löf & Olaison, 2020; Streeter et al., 2020). This suggests that queer people may not enter nursing home care even when they need it. An older gay activist in Canada described a meeting he attended on the topic:

We met with a health service [policymaker] ... and she wanted to know what each of us feel we would encounter if we had to go to a nursing home. Only one word came up: fear. Absolute fear.

Workers share these concerns, and do not feel safe to be “out” at work. Some have been cautioned to stay closeted on the job. A nursing home worker in Ontario said, “I got called into the manager’s office and she sat me down and told me, ‘I don’t think it’s a good idea that you talk about your sexuality on the floor.’”

These perspectives raise the question: Can publicly funded nursing homes produce dignified, respectful conditions of work and care for the increasingly heterogeneous populations of Canada and Sweden? We turn our analysis towards some promising possibilities.
EQUITABLE, DIVERSE NURSING HOMES? FUTURE VISIONS

What would an equitable nursing home look like? How could it be organized to offer living, thriving, dying, and working with dignity and respect for all involved? We recognize that efforts to create equitable spaces and relations come at a cost: to traditional values, principles, and ways of doing things, as well as financial costs. We also recognize that approaches to diversity may be configured in multiple ways, as different contexts may require different approaches, and that each approach has its intrinsic tensions that may simultaneously advance equity and challenge it. Our goal in addressing diversity is not to accentuate difference but to advance equity by reflecting the changing needs of those who live, work, and die in nursing homes as well as the constellation of communities that support them.

We draw on case examples from Sweden and Ontario, Canada, to discuss three approaches to this challenge. One approach has been to develop culturally specific nursing homes designed for and restricted to a particular population. A second approach is to develop culturally specific nursing home units within a nursing home. A third way is a more multicultural approach. This could be a culturally specific nursing home that will accept a wide range of residents but reserve a certain number of spaces for community members, or a nursing home that has made a commitment to recognizing and celebrating the many people who live and work there, developing an environment that overtly embraces the challenge of moving towards equity. As became clear in our research, however, all approaches to addressing diversity bring tensions due to the differences among groups.

Culturally Specific Homes and Units

In both Canada and Sweden, designated culturally specific nursing homes are a well-received direction (Jönson et al., 2018). Evidence from the United States and Australia suggests that ethnic minority residents living in mainstream nursing homes tended to have poorer health and social care outcomes than other residents, and those living in culturally specific homes fared better (Li & Cai, 2014; Runci et al., 2012; Shippee et al., 2016). The benefits of living in a culturally specific home are described as a sense of cultural safety and familiarity, being able to communicate in the language residents prefer, enjoy familiar cuisine, and participate in culturally specific activities. What goes unmentioned in most reports and articles is the safety and comfort offered by environments relatively free from racism, homophobia, xenophobia, or antisemitism.
Culturally specific Chinese nursing homes have been developed in many cities in Canada, with most staff and residents sharing Chinese ancestry. Cantonese and Mandarin are spoken, along with English, and Chinese culture is reflected and celebrated. A typical Chinese-specific nursing home in Ontario was founded by the local Chinese community and operates as a non-profit charitable nursing home. The board of directors comes from this community, as do most of the staff. The physical setting includes Chinese and English signage throughout the building and gestures to traditional Chinese symbolism in its architecture. Food, celebrations, language, traditions, and family involvement aim to address the different needs of residents who are from the Chinese-Canadian community. Like most culturally specific nursing homes across Canada, this home has a long waiting list, with an average of ten people waiting for an available bed at any given time in 2021. The home has also developed a personal support worker training program that includes skills in culturally specific care. This home serves a large and growing Chinese-Canadian community which provides significant financial support in the form of charitable donations that supplement government transfer payments and allow for some additional staffing and programming.

Culturally specific nursing homes have been established in Sweden, including a Jewish nursing home that first opened in 1945 to meet the needs of Holocaust survivors coming to Sweden from other parts of Europe. Other nursing homes include Finnish homes opened in the 1980s and 1990s, a Spanish home, and Persian- and Arabic-speaking homes in Stockholm (Jönson et al., 2018).

Some nursing homes offer small culturally specific “units,” sometimes a whole floor, within a larger nursing home structure. These units typically offer commitments to specific immigrant groups, ensuring some staff on all shifts speak the language, signage is bilingual, and celebrations, activities, and food reflect cultural preferences. Units for 2SLGBTQIA+/HBTQ adults are also emerging, responding to the need for culturally safer care. The first nursing home to facilitate care for older HBTQ persons in Sweden opened in 2021. Located in Hanveden, a suburban municipality near Stockholm, it is owned by the private provider Frösunda, and consists of several units, including a “Rainbow Unit.” This unit is designed for Gay, Bi, Trans and Intersex persons and/or older people with strong solidarity with the world of HBTQ. The Swedish Federation for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex rights (RFSL) was also an influential partner in the design of these units, and all staff working at the unit are educated by RFSL in gender variance.

In our research, culturally specific homes may generate tensions because cultural specificity rests on an assumption that one identity is primary in people’s lives and identities, and intersecting social locations – such as gender,
race, class, ability, sexuality, and other divisions – are secondary considerations. As one older adult involved in advocacy to improve nursing home care for the 2SLGBTQIA+ community told us, “There are all kinds of divisions within the queer community. We’re not as united together as we advertise. So this is a problem when things get downloaded to that community” (Ontario).

Cultural or linguistic specificity does not erase other differences within cultural and linguistic groups. For example, a Jewish home in Canada offered regular Reform and Orthodox services but recently added Conservative services following requests from residents and families. The home offers a social group for Russian speakers and has made efforts to survey its Jewish resident population and their families, to better understand their diverse needs.

Significant and unanticipated challenges sometimes emerge. In an Ontario nursing home offering care with attention to linguistic and cultural needs, we learned that a male resident originally from Somalia was putting pressure on women workers of Somali descent to provide him with sexual attention. He did not harass workers of other backgrounds. One of the women workers of Somali descent told us,

This is not uncommon. Many of our men of his generation think they have a right to our women. And with some women from our community, a man like him could get away with that. They would feel a sense of obligation. I won’t go into his room, I don’t even talk with him, although we speak Somali. My manager supports me.

**Multicultural Approaches**

In Toronto, Canada, one municipally owned home has a designated floor or unit for each of Cantonese, Farsi, Jewish, Korean, and Mandarin cultural groups. As residents, staff, and visitors navigate the home, they move through environments that reflect the city neighbourhoods in which they are located, hearing many languages and seeing signs of many cultures. Another home has French and Ismaili units, another provides care in Italian, Portuguese, and Polish.

While offering culturally specific conditions and attention to language in direct care relationships, these homes also resist “enclave” critiques and produce conditions that allow the homes to respond both to existing and emerging cultural groups in a city with rapidly shifting demographics.

In the city context, this approach to nursing home care offers promise, addressing resident needs for linguistic and cultural specificity and equity. Reflecting the city, including its dynamic multicultural environment, these nursing homes allow residents, families, and staff to be exposed to and participate in the activities and celebrations traditional to many cultural groups. Staffing these homes to ensure that at least some staff on all shifts have the
necessary linguistic proficiency for each unit presents significant logistical and human resources challenges, however. Because the municipality operates many homes across Toronto, the staffing pool is more extensive than if they ran only one or two homes. And while public ownership is not a necessary condition for providing this approach, public oversight and advocacy were factors in producing it, and it is supported by wages and working conditions that are generally better than those at for-profit nursing homes. These nursing homes may well be preferred employers, resulting in the relatively stable staffing on which this approach relies.

Whether a nursing home is entirely culturally specific or offers a culturally specific unit, or has a more multicultural approach, it can only operate in a context where cultural groups are large enough to produce both consistent needs for care and human resources to meet staffing requirements. In many smaller communities, and for small linguistic and cultural groups, these approaches are not a solution.

**Culturally Safe Work**

In our research, we have observed many efforts to meet the cultural and linguistic needs of individual residents. We have also witnessed the result of failures to do so. In both Sweden and Canada, despite promising developments and policy environments that are making significant strides on the legal and regulatory frameworks that support culturally safer, more equitable conditions, there is a long way to go to provide culturally safer nursing home care to all those who need it. And yet to be investigated is the impact on diverse staff of the different approaches to culturally safer care. If the conditions of work are the conditions of care, how can working conditions respond to produce culturally safer, more equitable conditions for an increasingly diverse labour force? We conclude our chapter by considering this question.

Both mainstream and culturally specific homes in Sweden and Canada employ workers from the specific populations they serve and from many other backgrounds. And the numbers of immigrant workers are increasing.

When I moved here in 2014, there were few Indians here. So that time when we went out people were staring at us like ... where are you from? Like why you are here like that? … Now, I think in [this nursing home] we have more than 30 people working … Yeah, we get together during festivals.

Nursing home staff members’ cultural background, language, ethnicity, and sexuality tend to be dismissed or downplayed in diversity initiatives, in preference to a focus on residents’ culture and language. This approach is reinforced by the understanding that the residents cannot leave to go to a more culturally
sensitive space, but that workers can and do. Yet we have noted repeatedly that diversity work within nursing homes tends to fall to workers from identified groups in ways that add to their workload but that is not counted in their job description. A queer British Columbia nurse described her work to orient the continual swirl of new workers and new residents around 2SLGBTQIA+ care questions. She reflected on her perpetual uncertainty about how new people will react, and how she had inadvertently become responsible for providing education in addition to her defined role because of her gender identity:

There is such a high rate of turnover among staff... like 30 percent or whatever it is. It’s continuous, well, here is a new person and what can I say and not say? And it’s ongoing. When a new resident comes in, or you know, a new staff, I never signed up to be the top lesbian!

At the same time, inequities and disrespect are often the unintended but real effects of a failure to attend to workers’ social locations. In a Dutch home in Canada, for example, posters promoting a charitable campaign featured images of starving Black children in Africa. These images were the only reference to Black lives and realities in the artwork and cultural representations throughout the entire institution, despite the many Black people who worked there. Both racialized and non-racialized workers in the home told us how troubling they found these images, especially in the context of the histories of Dutch colonialism in Africa and the Caribbean, yet they felt unable to protest or change this situation.

Storm and Lowndes (2021) suggest that in Swedish nursing homes, racism experienced by staff is often addressed by reorganizing their work. This is facilitated both by Sweden’s relatively high staffing levels and a commitment to “working it out” with residents, meaning that racialized staff are expected to “build trust” with residents. In Canada, high work intensity, lower staffing levels, and the reality that racialized staff tend to be allotted more precarious work arrangements leave workers with little power to complain about racism. Some do, and unions have been active in advocating for them, but there is a long way to go.

Attending to workers’ social locations offers an opportunity for them to connect with and relate to residents. Workers, and particularly front-line care workers, cleaners, and program staff often develop intimate relationships with residents, even in Canada’s stretched staffing conditions. A multicultural approach that acknowledges, values, and validates culture sharing could potentially enhance these relationships, both improving care and offering a safer and more welcoming working environment. Racism, sexism, homophobia, and xenophobia within staff teams, as well as among residents and families, could be explicitly identified and addressed. Given the growing shortages in care
labour, workers may find more possibilities for action to build culturally safe working conditions, and employers may be more inclined to develop equitable conditions in order to retain their labour force.

Workers’ language skills matter. In all the nursing homes in which we have conducted research, there has been an established lingua franca for nursing home staff. This language was Swedish in Sweden, and English or French, and occasionally both, in Canada, including in culturally specific nursing homes. A common language is important to competent professional practice for frail, sick, and disabled people. And the complexity of nursing home care means that workers must communicate within their occupational category, across disciplines, and with lay people, including residents and families (Kuznetsov et al., 2022). In countries with languages seldom spoken outside of the country, like Sweden, most immigrants arrive unfamiliar with Swedish and work hard to acquire Swedish literacy and verbal proficiency. In Canada, many immigrants know English or French, and were even educated in these languages. But they are often shocked by and unfamiliar with the vocabulary, syntax, grammar, and shades of meaning in use in the Canadian context. For immigrant workers in both countries, acquiring the language of their occupation or profession as used in these contexts, and learning how to communicate with other groups, adds layers to their learning. As Kuznetsoz and colleagues (2022) point out, these workers must acquire these complex language skills, rather than formal language proficiency. Acknowledging these workers’ languages of origin does not erase the need for common language(s) of practice.

TOWARDS EQUITABLE WORK AND CARE

Any future for nursing homes in countries like Canada and Sweden requires attention to the changing populations of residents and workers whose relationships are at the centre of care. As population heterogeneity continues to grow, more and newer immigrants will both need care and become care staff. As more older adults have lived their lives as “out” 2SLGBTQIA+/HBTQ community members, they and their families will insist on having their care needs met appropriately.

There are many possible directions for change. In 2022, the second author studied a Danish nursing home located in a neighbourhood entirely owned by a workers’ collective. The nursing home had established short-term housing for new staff, where those new to the city could live for up to 22 months at low cost and become a part of the community. This program supported many new immigrant workers. The nursing home also housed the community bowling alley, swimming pool, and target shooting range, and community members flowed in and out of the home every day. In many ways, the nursing home was a seamless part of the community, as many of the residents had lived in the
area for years. Because the neighbourhood was owned by the workers’ cooperative, housing remained affordable for nursing home workers, and many lived nearby. Some had raised their families there, and seen their children acquire an apartment and raise their own families in the neighbourhood. The multicultural staff included many racialized workers and some of the residents were immigrants from Africa, the Middle East, and China.

While this well-staffed nursing home did not offer cultural- or linguistic-specific care, it was able to meet many of the cultural needs of its diverse resident population. This was in large part because of its community relations, its connections to local Christian and Muslim faith communities, its volunteer group that put on a weekly Friday “happy hour” for residents, among other activities, and the many groups who used its recreation facilities, sometimes with residents participating or watching. Staff acknowledged that the pandemic lockdowns had eroded these relationships, but they had worked hard to restore them. In this home, the diversity of resident and worker ethnicities, languages, religions, and sexualities was widely discussed, not as a divisive problem that must be solved, but as an indicator of their success as an organization that aspired to truly belong to this diverse community. Tensions were addressed pragmatically, but without tolerance for racist, homophobic, or xenophobic behaviour or language.

Creating equitable, diverse organizations in a world fraught with inequities and oppression is challenging work. Nursing homes are not the organizations that people consider when looking for examples. In Canada and Sweden, the legislative and regulatory contexts promote attention to equity concerns, although somewhat differently, but both workers and residents from immigrant, racialized, and queer communities continue to experience disrespect and unsafe conditions. There is little research on whether and how culturally specific resident care affects workers, and almost no research on how to address diversity and linguistic needs in the context of high resident and staff heterogeneity, but the potential for such studies has never been greater.

NOTE

1. This article draws on data from the following empirical research studies: COVID-19 and Seniors at Home (Principal Investigator Susan Braedley, Carleton University), SALTY: Seniors Adding Life to Years (Principal Investigator Janice Keefe, Mount Saint Vincent University), Age-Friendly Communities in Communities: International Promising Practices (Director Tamara Daly, York University), and Reimagining Long-term Residential Care: An International Study of Promising Practices (Principal Investigator Pat Armstrong, York University).
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9. Regulation and accountability in the care home sector: expert commentaries

Albert Banerjee, Hugh Armstrong, Pat Armstrong, Frode F. Jacobsen, Charlene Harrington, and James Struthers

INTRODUCTION

The Re-Imagining Long-term Care team has studied regulations and accountability across different jurisdictions in Canada and internationally. The team brings diverse disciplinary perspectives to this topic and expertise from and across a variety of jurisdictions. In this chapter, you can hear from several of the team members. I (Albert Banerjee) approached a number of team members who have extensively studied accountability and asked them to share some of the most salient insights and lessons they have learned through their work. In some cases, we sat and had a conversation, which I then edited and passed back for their approval. In other cases, they submitted a short text. This gives the chapter the flavour of a series of conversations, something akin to a panel discussion.

We begin with a commentary from Pat Armstrong and another from Hugh Armstrong, who get the discussion going by outlining a broad set of principles that are essential for ensuring that accountability practices contribute to good care. We then turn to Jim Struthers, whose historical analysis shows how important it is to understand the past to deal with our present situation. There are also notable differences between jurisdictions, and Charlene Harrington shares some promising regulatory practices that have been enacted in the United States to hold for-profit providers accountable. It becomes clear that one of the most important concerns from both an accountability and quality perspective is preventing, reducing, or eliminating for-profit participation in care. But even in jurisdictions with limited for-profit participation, accountability practices still matter, as we hear in Frode F. Jacobsen’s commentary. Writing from Norway, he shares the promise of a more interpretive and collab-
orative approach to accountability that works with nursing homes, managers, and workers to continually improve care. We begin with a commentary from the research team leader:

**Pat Armstrong**

*Distinguished Research Professor Emerita, Department of Sociology, York University, Ontario, Canada*

What have we learned are the biggest issues in long-term care? Two of them are undoubtedly ownership and staffing. And they’re related. If we’re going to regulate, that’s where we have to start.

Unfortunately, regulation tends to start at the other end. It starts primarily in response to crises. Jim Struthers (see his commentary below) has written about this in the context of Ontario in the 1950s, and how private nursing homes at the time provided scandalously poor care. That’s when we here in Ontario first moved to regulation. The critical part of that move was to set up public care homes. Supporting the development of this public system (and non-profits) is essential. A growing body of evidence demonstrates that for-profit facilities, and especially international chains, provide inferior care and working conditions. Yet in Ontario, what we have seen is a combination of regulation and deregulation that amounts to an affirmative action plan for corporations. And if we are going to allow for-profit homes, then they really need to be regulated, and that regulation must be strongly enforced, because for-profit homes will work to find ways around regulations, and we have no reason to be confident in their reporting (see Harrington’s commentary below).

The second area where clear regulations are essential is staffing, remembering that the conditions of work are the conditions of care. This goes well beyond the numbers of people working, their pay and benefits. It also involves the proportion in terms of skill mixes and how many people are employed full time. Of course, there is always a risk that in setting minimums these become the maximum, but clear regulation here would be better than what we have right now. Staff also need the autonomy and team support that allows them to respond to individual needs based on their skills.

Without addressing the issues of staffing and ownership, we end up with more and more detailed regulations and laborious monitoring that get in the way of good care. As we have learned, the quality of care is very hard to measure. Often what happens when regulating is that what counts is what can be counted. This is usually not the most important from residents’ and staff’s perspectives. Plus, if you spend a lot of time having people check off lists, then you’re undermining the quality of care because they spend too much of their time doing that.
Instead of such detailed regulations, it is useful to establish principles – standards rather than standardization. Some key principles would be a recognition that the conditions of work are the conditions of care, that care is provided through relationships, that care focuses on residents, and that staff, residents, and their families need to be empowered in meaningful ways. Regular inspections for proactive purposes would be guided by these principles. Moreover, principles are open to discussion, a means to continually improve.

Another principle should be continuing education. Ensuring that staff have the tools and skills they need, and that they can acquire those regularly on an ongoing, hands-on basis. Fostering teamwork also matters. It reminds me of the old sociology adage: How do you keep your neighbourhood safe? You do so by knowing your neighbour and having people sitting on the front porch. You are much more likely to get quality when staff know the residents, when staff are working together, when there’s someone watching, and, more importantly, when there’s someone helping. You don’t need regulations stipulating the resident maintain a 90-degree angle of hips, knees, and ankles while eating, if you have staff with appropriate training and sufficient supports who are watching and helping.

To give an example: as we saw in Sweden, staff teams routinely sit together to discuss how to improve care. We saw the same thing in Norway. An occupational therapist was really pushing a man to work on his own. When I asked her if she was worried about falls, she replied, “Well, sometimes they fall. But my job is to push them to their capacity so that they keep those capacities. Of course, we try and avoid them falling. But if they fall, we talk about how that could have been prevented.” Falls don’t get automatically reported and used against the home, as they would in North American regulatory systems.

Ensuring staff understand quality is another important principle. I am reminded of a home in Manitoba where the manager had really thought a lot about this. One of the things she did was to make sure everybody was either full time or permanent part time. When a new full-time position came up, whenever possible she hired from the permanent part-time category so that people knew the residents and knew what mattered to them. We are not talking about quality in some abstract sense, but about what matters to this resident now. She made sure that the receptionist took a menu to every resident every day so that she would know them. The laundry person took the clean laundry to residents’ rooms as well. That way, they could have a chat with and get to know residents. That kind of knowledge of residents, spread to everybody who works in the place, is essential for quality. Another thing the Manitoba manager did was ensure that every new staff member was bathed by the other staff members, just as they bathed the residents. One man we interviewed said, “Even though they let me keep my bathing suit on, I have never felt so vulnerable!” This kind of experience really transforms how you work. Of course,
you can’t do that unless you have the time and help, which takes us back to ownership and staffing.

**Hugh Armstrong**

*Professor Emeritus, School of Social Work, Carleton University, Ontario, Canada*

Let me share a few things that have stuck with me from my time as co-chair on the Re-Imagining project’s accountability theme group.

First, accountability is usually implemented in a top-down manner. That is to say, the people at the bottom are accountable to the people at the top, whether it’s to the management of a home or the management of a chain of homes or the government. Accountability should not work only that way. Those at the top should also be accountable to the residents, the workers, the families, and, more generally, the public. That’s fundamental. Bottom-up accountability is not simply a matter of electing a new government every three or four years based on a wide range of issues, or more accurately the avoidance of a wide range of issues, as was the case in Ontario in June 2022.

Second, accountability should not be seen primarily as an individual matter – in other words, individuals being held accountable for their actions. Accountability is a collective matter. Much of accountability in general, and regulation in particular, have to do with structural matters, such as staffing levels and mixes, and financing. They have to do with what the government or the managers of chains, or individual facility managers do or do not do, which affects work all the way down the line. To give an example with regards to infection prevention, we need to ask: Is there an inventory of personal protective equipment? Is it easy to access? Is it readily distributed or are there barriers to access? These are determined by decisions made at the top that those at the bottom must live with.

Unfortunately, the bottom-up approach to accountability is not the one taken. Regulation, for instance, tends to be a matter of detailed instructions to those at the bottom. And all too often they are implemented in reaction to scandal. The problem is not that workers are lazy or ill-trained. The problem is the conditions under which they work. This reflects, in part, what Pat said about the conditions of work being the conditions of care. There needs to be an accountability from the top: for example, to fund appropriately, to hire appropriately, to train appropriately, to design facilities appropriately. These are all conditions under which those at the bottom have to work and there should be mechanisms to make those above you accountable to you, as well as you being accountable to them. Throughout the entire system, it should be a two-way street.
To give another example, there’s the reliance on the Resident Assessment Instrument – Minimum Data Set (RAI-MDS), which is a key component of the system of accountability in Ontario. It is a measurement system that is very top down. In fact, the workers seldom know what the overall impact of the assessment is. And residents certainly don’t know what the numbers mean for the home, unless they happen to learn the system of indices of falls or ulcers. The federal and provincial governments produce such measures by combining a whole lot of elements together. You don’t know how they combine them, in part because they’re so complicated. The RAI-MDS is also overly medical, and care is a social matter, as much if not more than it is a medical matter.

We know that these assessments take a lot of time and energy. They distort care. For example, you see a personal support worker (PSW) with three or four residents at a little dining room table. She has a laptop on her lap, and she’s trying to measure how many ounces or milliliters of liquid go into each of the residents’ mouths. This is not the way things should happen! There should be much more autonomy for individual workers. PSWs should be given the tools and scope with which to make judgements on how much time to spend with each resident and not have to devote time to clicking on a laptop. The RAI-MDS may also be a source of resentment in that, at least in Ontario, facilities designate somebody who coordinates the information and gets it into the centralized system. That staff member is often in a separate room burrowing away on a computer when there’s a lot of care work to be done. There are real problems with RAI-MDS and the top-down approach to accountability more generally.

The countries that promote the autonomy of workers do not promote top-down accountability. It’s much more bottom up. Let’s imagine there are 12 people in your unit. You as a staff member and the three other people working there can figure out how to organize the work that needs to be done. We'll make sure you get enough food freshly delivered as often as needed. We'll make sure that you've got a decent fridge and stoves and microwave and whatever else you need. You will also be responsible for a wider range of things, including perhaps some housekeeping. In one of the Swedish homes I studied, each unit not only had its own toilet facilities for a single person, but its own laundry. It had a stackable washer and dryer. That means that either the resident or the worker or both could put the laundry in every day or two. The larger linens and towels get done elsewhere in the facility or off-site. But the clothing can be done right there, on a delicate cycle, if need be, giving more autonomy and control to the resident and staff. It becomes part of the regular day. It also means that you keep the hallways smelling fresh because they don’t have soiled laundry in them. And with kitchens on every floor you also bring in other welcome aromas. There are lots of little things you can do that don’t cost much and support autonomy at the bottom.
James Struthers

Professor Emeritus, Canadian Studies, Trent University, Ontario, Canada

One of the challenges that we face when thinking about accountability, particularly in Ontario, is that the nursing home sector did not evolve in a planned, integrated fashion. It evolved in an ad-hoc manner, under different ministries, guided by different motivations – from eliminating “bed-blocking” by the elderly to creating profit opportunities. A historical perspective is helpful in understanding how our current regulatory framework evolved, and where we may go moving forward.

Let me give you some context for the situation in Ontario. There are really two paths to the modern old-age home in the province. One, which emerges in the late 1940s, in response to a heightened postwar climate of social citizenship, is the transition to tear down the poor house and build a new suburban, modern home for the aged that looks like a resort or a motel or a friendly place to be. The second track is a response to hospitals getting overcrowded, which occurs at the same time. There’s an increasing demand for what would eventually become universal hospital insurance, which arrives through the Hospital Diagnostic Services Act of 1957. As a result, hospitals in the 1940s begin pushing to find alternative places for their chronic care elderly. But they can’t be discharged to the new modern homes for the aged because they’re not designed to be medical facilities. They’re not designed to provide chronic care. Also, their residents don’t want to be surrounded by demented, chronically incapacitated people. At this time, the residents in homes for the aged were much more functional; many residents were still driving even, and the parking lots were for them as much as for family and staff.

So municipal governments that were responsible for public care in hospitals entered into agreements with private boarding house owners, usually “mom and pop” operations, which in the 1920s and 1930s were usually running a boarding house operation for single men or single women. But with the arrival of universal old-age pensions after 1950 for those aged 70 and over who were now getting $40 a month, city governments started saying, “Hey, can you take in some of these people we are seeing as bed-blockers out of our hospitals? They don’t need doctors, they don’t need nurses, but they do need somebody to look in on them now and then. They need to be fed. They can’t cook for themselves. They need companionship.” That’s the second stream, and that’s the one that really has more connection with where we are now.

The for-profit private nursing home sector evolves from the 1950s onwards, ultimately forcing governments to get involved in more and more regulation. Ontario passes its first nursing home inspection and licensing act in 1966, in reaction to a wave of negative media coverage of the abuse of residents in
overcrowded and understaffed private nursing homes throughout the 1950s and early 1960s. It’s not until the mid-1960s that the province is in the business of licensing and approving, and then inspecting and subsidizing, a soon-to-be mostly for-profit sector.

After 1972, the nursing home sector gets permanent funding from the Ontario government through the Extended Care Funding Plan. And for the next 30 years they’re on separate tracks from Homes for the Aged, which are funded through the Ministry of Community and Social Services which, as its name implied, operated on a social services mandate. The nursing homes and the homes for the aged have separate ministries, separate statutes, really separate models of care, but for increasingly similar populations.

When the left of centre New Democratic Party gets elected unexpectedly in 1990, for a long time they debate eliminating private, for-profit care altogether. But in the end, because of a sharp recession, and by the time they are facing an election in 1995, they simply merge the two sectors into one under the Ministry of Health. And we end up in Ontario with the largest for-profit nursing home sector in Canada. By far. Almost 60 percent of the care homes are for-profit.

And now all the homes operate under a convoluted set of regulations developed primarily in response to scandals emanating from abuses occurring in the sector.

For the last three decades, prior to Covid-19, this was a crisis just waiting to happen to expose all the frailties, the gaps, the lack of planning, the misdirection I am trying to explain as an historian. To understand where we are, it is helpful to recognize that the Ontario system evolved piecemeal, governed by different ministries in different times, dealing with different motivations, whether it’s reducing shame and stigma, or freeing up hospital beds, or creating for-profit opportunities for former rooming house operators.

One way to bring coherence to the sector is to regulate it as part of Medicare, which would of course force the elimination of the for-profit sector. We still haven’t done that. And now we’ve had two major Royal Commissions that have said long-term care should be part of Medicare. Will the aftermath of Covid-19 bring a change? We must make it our priority.

**Charlene Harrington**

*Professor Emerita, School of Nursing, University of California, San Francisco, United States of America*

In the United States, where I live, the for-profit sector has a primary focus on profitability for owners and shareholders and a secondary focus on providing care services. As a result, in the US and in regions with an established or growing for-profit sector, there are three areas of regulation that are par-
ticularly important. These areas are: (1) staffing standards and transparency, (2) ownership and management transparency and accountability, and (3) financial transparency and accountability. We need clear regulations and strong enforcement in these areas. I want to briefly consider some hard-won, promising examples.

STAFFING STANDARDS AND TRANSPARENCY

Many for-profit nursing homes make money by cutting their staffing levels and wages and benefits. Minimum staffing standards are important to ensure adequate care to residents. Transparency in reporting accurate staffing data is essential to regulatory oversight. In 2008, the US passed legislation requiring all nursing homes to report the details of all their daily nurse staffing from payroll records (Patient Protection and Affordable Care Act, 2010). The reporting system established in 2017 provides detailed information on the number and type of daily nursing hours at each nursing home. This staffing information is publicly available on the government’s nursing home care website to aid consumers in selecting and monitoring nursing homes. It is used as a key component of the government’s quality rating system. And it is used by state surveyors as part of their inspection and enforcement process (Centers for Medicare and Medicaid Services, n.d.). In 2022, the President launched an initiative to improve nursing homes by establishing minimum nurse staffing standards and vigorously enforcing staffing and quality regulations (The White House, 2022).

OWNERSHIP AND MANAGEMENT TRANSPARENCY AND ACCOUNTABILITY

Private investor acquisition of nursing homes is a concern because of the lack of transparency and the potential for adverse impacts on quality and costs. Private equity investments result in increasing the costs for facilities and capital, along with higher profit margins compared to other for-profit or non-profit homes (Government Accountability Office, 2011). A study of private equity (PE) buyouts of nursing homes from 2000 to 2017 found significant declines in resident health and compliance with care standards related to cuts in front-line nursing staff, compared to acquisitions by non-PE corporates and chains (Gupta et al., 2020).

Nursing homes with the worst quality of care are more frequently bought and sold than high-quality nursing homes (Grabowski et al., 2016). Ownership and management screening requirements are needed to prevent unsuitable and unscrupulous persons or companies from acquiring and operating facilities. For example, a US nursing home company, called Skyline Healthcare, col-
lapsed in 2018 after purchasing and operating more than 100 facilities in 11 states with more than 7,000 residents. The chain was unable to make its payroll and some states had to appoint receivers to take over management or close some facilities and move residents to other facilities. Charges of neglect were issued against the chain by some states (Flynn, 2019). The 2022 presidential initiative will create a new database that will track and identify the quality of care provided by owners and operators across states while enforcing greater transparency and accuracy in ownership reporting (The White House, 2022).

FINANCIAL TRANSPARENCY AND ACCOUNTABILITY

Governments often focus on controlling nursing home costs rather than ensuring adequate funding for staffing, wages, and benefits, and for direct care services to protect the health and safety of residents. In the US, the federal payment system is based on estimated nursing home costs and not on actual expenditures. The US government has an elaborate system to pay the costs expected to meet the staffing and care needs of residents based on their acuity. Once payments are made to nursing homes, however, the system allows nursing homes to keep staffing and operating expenses low, enabling profit maximization (Medicare Payment Advisory Commission, 2020). This allows excessive profit-taking by companies and poor care. The President reported that government agencies will examine the role of private equity, real estate investment trusts (REITs), and other investment in nursing homes, and improve financial transparency (The White House, 2022).

Another concern is that many nursing home companies establish related-party companies to contract with for services, thereby siphoning profits and administrative costs away from the nursing home into these related companies. These related parties include home offices; management organizations; staffing, therapy, supply, pharmaceutical, consulting, insurance, banking, and investment entities; parent companies; holding companies; and sister organizations. A new transparency requirement adopted in California in 2021 requires nursing homes to submit a consolidated cost report inclusive of data from operating entities and all organizations and entities related by common ownership or control (California Legislation, 2021b). Management companies and property companies that are not related by ownership should also be required to provide a full financial report annually.

Another new regulatory approach is to place a yearly ceiling on the spending on profits, administrative costs, and property costs of each nursing home, its related parties, and parent companies. Three states (New Jersey, New York, and Massachusetts) have passed such legislation, requiring that most expenditures are for direct care services (Stulick, 2021). In New York, the 2021–2022
budget legislation required that nursing facilities spend 70 percent of revenues on care, with 40 percent on direct care staff, and it limited profits to 5 percent (Long Term Care Community Coalition, 2022). California, where in 2020 only 64 percent of revenues were used for direct resident care, has proposed legislation to require 85 percent of revenues to be spent on direct resident care (California Legislation, 2021a).

These types of new transparency and regulatory efforts are designed to improve the staffing and the quality of nursing home care and to improve enforcement and accountability.

Frode F. Jacobsen

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One lesson learned from our research projects is that the larger the share of for-profits, the more comprehensive and complex are the systems of accountability. Avoiding for-profits in care or reducing the share of for-profits if they are already in the sector is one important way of reducing the burden of oversight and reporting that both decision-makers and front-line staff find exhausting. However, this does not mean systems of accountability and oversight are not important and should not be in place in jurisdictions where for-profits are absent or are only minor players. How accountability is practiced in these jurisdictions is an important matter for discussion.

I would like to consider several important dimensions of how accountability should be practiced in the care sector, specifically with regard to: (1) who is made accountable, (2) what they are accountable for, (3) how oversight is carried out, with the involvement of whom, (4) how the results of oversight are communicated, and to whom, and (5) the impact the results of oversight have on working conditions. And related to all these factors: Do systems of accountability support or hinder good professional care? This is a question we need to ask.

First, making all actors accountable and including all levels of decision-making are important for a system of oversight to work and to appear meaningful to all the people involved. A system primarily designed to hold front-line workers accountable is disempowering to care staff who are doing complex work that demands effort, a broad set of skills, and full dedication.

Second, many things that are easily counted should not be counted, especially things that do not actually measure care quality, like measures indicating natural disease progression in a frail population of older nursing home residents (Cefalu, 2011). Systems of reporting place a toll on staff, particularly the front-line care workforce. Time spent on reporting means less time spent...
on direct care. Hence, we must be judicious. Fewer items should be included and all of them must be essential to quality of care. Including direct care staff in the selection of items could help ensure their relevance. It would also offer front-line staff more control over their own work.

Third, jurisdictions with less for-profit involvement means not just less cumbersome and comprehensive systems of accountability; it also means less prescriptive and more interpretive regulations, which allows care workers more room to adapt to residents’ needs and preferences. The interpretive approach to regulation also enables a cooperative form of oversight, where the officers carry out the oversight work in close cooperation with management and staff of facilities or organizational units of home care. This is the case in some Norwegian municipalities, where those charged with oversight can help staff solve problems. They are not there just to punish bad behaviour.

Fourth, an important part of the accountability process centres on to whom the results are communicated, and in what form. Even in the less prescriptive and most interpretive regulatory environments, the results of oversight become part of the governing tools of local and central authorities. Moreover, in the Nordic countries and beyond, the results of oversight may be used for benchmarking and competition between organizational units, facilities, and local authorities. They can support the development of local practice and hence become an important means for front-line workers and first-line leadership to improve care where they work.

Fifth, the working conditions for front-line staff, when being subject to oversight at a local level, matter. Besides being properly staffed for physical and psychosocial dimensions of their work, it matters how much room they have for reflecting on their own work and practices. Allowing for proper oral transfer of knowledge is important and requires organizational support as it is more time-consuming than reporting electronically. Besides, complex here-and-now situations can best be conveyed orally, and many things that should be talked about should not get an eternal existence as part of a written record. Providing staff with ample room for reflecting on care situations and on their work could, in addition, be organized as dedicated time for staff group reflection. In Norway, political authorities may initiate and support such reflection processes. An example of this is ethical reflection groups organized by The Norwegian Association of Local and Regional Authorities (KS). These involve weekly group sessions that take place at a nursing home ward for half an hour or for a full hour. The point of departure for group reflection was often a specific case of a resident that raised some ethical concerns.

In conclusion, an effective way of avoiding overwhelming systems of reporting and oversight is avoiding for-profits in care. Whether there is a sizeable share of for-profits in care or not, systems of accountability cannot and should not be avoided. Rather, it should be a priority for decision-makers at all levels.
to limit the range of dimensions and items included in oversight, making sure that the dimensions selected make a difference to care, and find approaches to oversight that are empowering and improve care at the local level.

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Reading the commentaries of my colleagues, I cannot help but recall an interview I conducted with a frustrated member of Ontario’s non-profit nursing home sector. He observed that the sector is regulated in “all the wrong places.” As a result, the regulations are ineffective. Not only do they often not improve care, they make things worse, pushing standardization and taking time away from care in favour of reporting. What’s more, the compliance system has become so “byzantine,” as he put it, that the province cannot afford to implement it. Prophetic words. In 2020, Ontario moved to a complaints-based process because it did not have the staff to do the annual inspections. It created an understaffed oversight system to monitor an understaffed nursing home system. Subsequent policy changes emphasize punishing homes rather than supporting quality improvements.

By saying the province was regulating in the wrong places, he was referring to an over-emphasis on regulations of care workers rather than on regulating for-profits out of the sector. For-profit providers, as Charlene Harrington notes, have as their primary incentive the maximization of profits. If you have any doubt, attend a shareholders meeting. Or consider the 2020 report by the Senior’s Advocate of British Columbia, *A billion reasons to care*, which found that for-profit homes routinely under-delivered hours of care, whereas non-profit homes over-delivered. In Charlene’s commentary, we also get a sense of the cat-and-mouse game that is played when for-profits dominate. Stipulate a rule that a dedicated amount of the budget must go to medical care and staffing, and for-profits will buy the pharmaceutical supplier and staffing agency to extract profits from these areas. Or the for-profit corporations will create a company to rent land from or to manage the home, again as ways of extracting profits and getting around regulations. It’s not uncommon for one nursing home in the US to be comprised of tens of corporate entities, both to siphon profits and minimize the harm from potential litigation. And in this context, as Charlene has often reminded me, you do have to count baths, because without that, they will not be given. The regulatory system becomes increasingly complex. This is a path to avoid. This is also a regulatory decision, and as Jim Struthers points out, it is one that could be made by including nursing homes within Medicare.
The commentaries also point to the ways in which regulation can set the
conditions of care. They can support time for care by setting minimum staffing
levels. They can ensure skills for care by ensuring training. And they can play
an important role in creating an innovative culture of care. The interpretive
system that Frode F. Jacobsen refers to enables creative deliberation and
problem-solving. It helps nursing homes meet standards of care in ways that
are tailored for individual residents and specific contexts. This is not the same
thing as standardization, as Pat Armstrong rightly notes. It is also a manner of
fostering the bottom-up type of accountability and empowerment that Hugh
Arnold observes is sorely lacking in our conventional approach to account-
ability. What’s more, as Frode points out, compliance systems can work with
nursing homes to improve care. Compliance officers or inspectors know the
problems in a region. They also know how homes have set out to resolve them.
They can therefore be part of quality improvement. Again, this requires collab-
oration and trust, and we tend not to have that in a system with a high degree of
for-profit participation. This is, of course, not to say that public and non-profit
systems do not need accountability. But these systems can become more
collaborative and interpretive, and we can start to regulate in the right areas.

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10. Making joy possible in care home policies and practices

Susan Braedley, Pat Armstrong, and Janna Klostermann

Bread and Roses, a song long associated with labour and feminist struggles, has a famous line: “Yes, it is bread we fight for, but we fight for roses too.” For us, talking about joy is a way to articulate the “roses” pertinent to struggles for improved living conditions for care home residents and caring conditions for care home staff. Bread is a metaphor for the material conditions required for survival – bare life as some have described it (Agamben, 1998, p. 355). Roses are a metaphor for what makes survival worthwhile – the purpose, meaning, and connections that humans find in living, working, and relating with others. This is joy, in our definition.¹

How would care home policy and practice discussions, debates, and problem definitions shift if we began by considering joy? First, joy as a concept challenges the stranglehold of neo-classical economics and evidence-based medical knowledge on determining the terms, scope, and terrain of long-term care policy and practice. While we agree that medical knowledge is vital to supporting frail and/or disabled people to live and die well, medical care is only one dimension of care home quality. And while economic planning, measurement, and accountability are essential to ensuring public financial resources are used responsibly, healthy care home finances are an insufficient basis for healthy, respectful, dignified conditions of living and caring.

To sort out how care homes can offer the conditions to make joy possible, we need to apply knowledge from the social sciences and humanities. A consideration of joy asks us to augment so-called “cold hard facts” with “warm soft concepts” that are, in our view, no less rigorous.

While we are certainly not the first or only commentators to write about joy in nursing homes, our contribution here is to consider joy as a critical perspective or angle that questions the knowledge base used to determine how care home quality is organized and regulated. Our starting point is that joy is a socially determined need and potential in contemporary societies – part of what social groups must struggle to organize, along with “food, shelter, jobs, and babies,” as Pat Armstrong and Hugh Armstrong have argued
Care homes in a turbulent era (Armstrong & Armstrong, 2003). To live, and not just exist, humans need purpose, meaning, connection, and pleasure. Joy can be articulated in these terms, and the conditions that encourage and allow for joy can be measured in some ways – and have been, as we show here. Drawing on research examples from Canada, the US, Norway, and the UK, we provide an overview of the challenges of measuring care home quality, and consider the ways that joy is considered, ignored, or missed in most quality assurance measures and processes (Banerjee & Armstrong, 2015). Drawing on over a decade of research across many jurisdictions and projects, we then provide evidence on care home conditions that make joy possible.

PROBLEMATIZING QUALITY: WHERE IS THE JOY?

Different approaches to ensuring and measuring care home quality reflect distinct problematizations – or understandings of what the problem is – when it comes to inadequate care home quality (see Chapter 6). Across jurisdictions, regulators choose and use a variety of mechanisms and tools, influenced by their respective welfare state approaches, values, and politics. But most jurisdictions use tools that determine quality using knowledge claims from medicine and economics, while also showing differences in how they measure it. In Canada and the U.S, for example, the problem is not just to find reliable ways to improve quality across the system. It is how to measure care home quality in a way that translates readily to an enforceable regulatory regime (Van Malderen, Mets, & Gorus, 2013; Godin et al., 2015; Kehyayan et al., 2015; Daly et al., 2016; Armstrong, Daly, & Choiniere, 2017; Morris et al., 2018; Daly, Choiniere, & Armstrong, 2020).

This means finding comparable, standardized quantitative measures that assess resident health outcomes and economic efficiencies in a manner consistent with neoliberal commitments to public services privatization. In these jurisdictions, privatization is not touted as a solution to care quality problems, but as an antidote to lagging capital expansion and rising welfare costs. As a result, the problem of quality in these contexts has become less about how to ensure residents have the resources and conditions to live well, and more about how to prevent wily operators from cutting care to a minimum to extract more profit.

These governments, as both funders and regulators, aim for efficient, comparable quality measurements both to impose and to regulate quality across care home systems. Given the potential costs that quality improvements can entail for provider organizations, what and how to count to assess care home quality have become political questions involving high stakes and intense lobbying from for-profit companies (Meagher & Szehely, 2013; Choiniere et al., 2016; Harrington et al., 2017). Three common quality assurance approaches,
used sometimes singly, sometimes in combination, are: comparable clinical
data sets, inspections and audits, and certified models for care. So, what are
the strengths and problems of common approaches to quality assurance? Can
they assess joy?

Ensuring Quality with RAI-MDS: “Very quick and click, click, click”

The RAI-MDS (Resident Assessment Instrument – Minimum Data Set) is
a clinical data set used to measure care home quality in many Canadian juris-
dictions, across the US, and in other jurisdictions internationally. It assesses
resident health and care home quality via data collection that can integrate res-
ident medical data and economic performance measures (Armstrong, Daly, &
Choiniere, 2017). It not only assesses individual resident health care needs, but
provides aggregable data that, according to advocates, can be used to address
care quality problems across care home systems (Hirdes et al., 2011). In some
jurisdictions, care home RAI-MDS scores are used to determine funding
levels, with higher resident acuity (i.e., the measure of severity of illness or
medical conditions) allowing access to more funding (Daly, Choiniere, &
Armstrong, 2020).

The use of this instrument can improve some aspects of care by providing
a portrait over time of care home residents’ health and functioning, including
acuity. At the height of the Covid pandemic, for example, this instrument
allowed for detailed knowledge of care home residents’ overall changes in
health status, including rates of infection and death, and provided publicly
available aggregated data on each care home. This proved important to both
regulators and care advocates. It allowed them to organize both individual
care home and systemic responses and was a basis from which to raise critical
questions about care problems, including, for example, the effects of social
isolation on residents or the need for family support. Some have argued that
in the UK, where consistent publicly available resident health data was not
available, systemic responses floundered as a result (Hanratty et al., 2020;
Musa et al., 2020).

The insufficiency of data on resident care outcomes has been a critique
raised in many public inquiries and commentaries (i.e., Office of the Seniors
Advocate British Columbia, 2021; Szebehely, 2020). But it is also true that
available data is not always used effectively to both plan and respond to care
problems. During the early months of the pandemic, for example, the ample
available data on resident health in Ontario offered a rich basis for developing
a swift, effective systemic response. However, both government and long-term
care owners’ organizations failed to take advantage of this opportunity, as care
home managers have confirmed.
While useful in measuring illness and survival, the RAI-MDS instrument also limits what counts as care quality. First, quality of care is assumed to be present in the absence of medical issues and risky events such as falls, pressure ulcers, restraint use, and antipsychotic drug use. However, “[i]t is weak on questions of quality of life, as distinct from the quality of (medical) care” (Armstrong, Daly, & Choiniere, 2017, p. 355). As Doucet (2021, p. 12) has explained, instruments like the RAI-MDS “include, for example, the view that data is ‘given’, ‘waiting to be found’, ‘inert in and unaffected by the knowing process’ (Code, 2006, p. 41).”

The tool records data on individual outcomes, not structural and process conditions. It does not measure, for example, enjoyable mealtimes with fresh, seasonal, and culturally appropriate food; comfortable bathing experiences; participation in caring for pets, plants, other residents, or the home environment; or stimulating interactions with others. It is unable to capture opportunities to participate in musical, sport, artistic, or other activities that allow residents to use their talents and abilities. The tool ignores issues such as whether a full staff complement is working, or the home is short-staffed, or workers are doing overtime. It does not measure the presence or degree of cooperation and teamwork occurring within the staff group, characterized by “honest speaking, root cause analysis, and creative innovation” (Banerjee et al., 2021, pp. 6–7), although this teamwork has been shown to improve care quality.

By relying on the RAI-MDS as a “quality” measure that focuses on residents’ health, care homes are encouraged to prioritize action that could reduce or eliminate individual medical care issues. It means that structural and process changes that could improve care home life – such as higher staffing levels and more staff education, more time allotted to resident support, enhanced food budgets and in-house food preparation, and enhanced recreational programming (Banerjee & Armstrong, 2015) – tend to slide down the priority list.

Second, the RAI-MDS instrument influences care in a less direct but significant way. Accurate, complete data entry is part of the required accountability to funders, in terms of both quality measures and, in some jurisdictions, funding levels. As a result, care home managers must make data collection and entry the top priority, even before resident care (Kontos, Miller, & Mitchell, 2010; Daly, Choiniere, & Armstrong, 2020). In many care homes, some workers are assigned full time to data input, shaping divisions of labour that mean fewer staff are available for and involved in care teamwork. One family carer of a resident in an Ontario care home described the result: “They [the staff] become very quick and ‘click, click, click,’ you know, ‘here’s your medical diagnosis, this and this,’ and they don’t take time to know the person or to hear what the person has to say.”
Adding metric joy indicators will not solve these measurement problems for regulators. Joy as an outcome is not amenable to objective, quantifiable, comparable measurement. Unlike blood pressures, number of falls, grams of liquid, or bowel movements, joy cannot be counted. Yet, quantitative comparable measurement is at the beating heart of neoliberal publicly funded care home regulation, and regulation is increasingly the main tool these governments use to influence quality, although with considerable variation in how this is accomplished (Lloyd et al., 2014). Considering joy suggests that these approaches to quality improvement do not have the capacity to evaluate or make substantive improvements to care home quality of life and quality of care. It isn’t that quality cannot be improved across systems, but that the emphasis on quantitative comparable measurement requires a kind of data collection that not only is incapable of capturing the conditions for joy but shifts organizational priorities away from those conditions.

Ensuring Quality with Inspections and Audits: “Our best foot forward”

So, if joy cannot be assessed or approached by the RAI-MDS type of measures, do inspections or audits offer a way forward? Used in many jurisdictions, often in addition to the RAI-MDS, inspections and audits focus on observable indicators, including what can be detected from record-keeping, interviews, tests, and observations throughout a care home (Choiniere et al., 2016). It seems entirely possible that the conditions for joy could be noted, assessed, and supported through these processes, if conducted in person by inspectors with a mandate to do so.

Regulators in many jurisdictions use care home inspections or audits as a quality assessment tool, using a wide range of categories for evaluation and with processes that vary in their degree of standardization across care homes, or from year to year. Inspection processes differ in how they work towards quality improvement, and can be mapped along a spectrum of “compliance” and “deterrence” regimes (Walshe, 2001; Choiniere et al., 2016). These processes range from collaborative assessments that support quality improvements via recommendations and education, to highly quantified audits that can impose severe financial and reputational penalties for non-compliance.

While legislation and rules outline how inspections are supposed to work, it is also worth noting that political and other context-specific factors can diminish their effectiveness. In the U.S, for example, state-funded for-profit care homes are the norm and deterrence-style care home audits called “surveys” are required by federal regulation and can incur high financial penalties for provider organizations (Boehmke, 2018). Research conducted across 16 states showed that care homes and managers that made campaign contributions to state regulators had more positive inspection reports: “Overall, these results
produce evidence that contributions decrease the total number of deficiencies cited per survey and strong evidence that contributions reduce severe deficiencies” (Boehmke, 2018, p. 455).

So, although inspections offer promise as a quality assurance measure, the degree to which they can measure the kinds of conditions we raise here depends on how inspections are organized and supported. Many inspection processes call for extensive preparation at the care home, taking staff time from care. In Canada, we have heard about cases where care home managers brought in extra staff and equipment when inspections were anticipated, in an effort to get a better assessment. As one nurse manager in British Columbia put it, “Our staff recruitment, our reputation within the community, even the ease in getting approved for different initiatives from the health authority, are all affected by our inspection reports. Of course, we staff up and put our best foot forward.” In some jurisdictions, concerns have been raised about under-staffed inspection teams that are unable to keep up with the required inspection schedule, creating backlogs (Investigate Europe, 2021) and raising questions about the conditions for producing these inspection reports. Many jurisdictions cancelled inspections during the Covid pandemic, at a time when residents and staff were most at risk and most in need of support (Chapman & Harrington, 2020; Russell et al., 2021). Clearly in these jurisdictions, inspections were not considered a support to quality so much as a report card exercise, easily delayed until the “marks” would be higher.

Of course, care home quality oversight occurs in other ways: as the result of public inquiries into scandals or catastrophic events, in response to extraordinary circumstances, or as part of the fiduciary or legal oversight of public operations (Lloyd et al., 2014; Estabrooks et al., 2020). In Ontario, Canada, for example, when early, severe Covid infection outbreaks and related visitor restriction led to drastic care work shortages (Armstrong & Klostermann, 2023), military health care services were called in to assist in the most abysmal care home situations. The military wrote a damning report on the conditions in these care homes, describing appalling conditions and quality issues well known to those involved with the sector (Taylor, 2020). Recently, the Norwegian Parliamentary Ombud inspected some Norwegian nursing homes, as part of its mandate to prevent cruel treatment, coercion, or punishment (Sivilombudet [Norwegian Parliamentary Ombud], 2021), and raised concerns about coercion in dementia care situations. However, these inquiries, reports, and other investigations usually assess just a few dimensions of care home quality and aim to describe and address problems, rather than to identify promising conditions that support quality of life and quality of care. In general, they have had minimal success in fostering improvement.

We can conclude, then, that adequately funded and staffed inspections and audits have the potential to assess quality, including the conditions for joy.
However, if these inspections are highly punitive or function only as “report cards,” as opposed to educational and collaborative processes, care homes and inspectors will have incentives to circumvent or “play” the system. In jurisdictions with a high percentage of for-profit ownership, industry lobbying and political pressure around inspections appears to be more developed. Finally, many inspections, audits, and inquiries emphasize problems and make recommendations for amendment. These recommendations are often ignored and forgotten until the next time the problem reoccurs.

**Ensuring Quality with a Certified Care Model: “A system tool for nursing homes”**

Another approach to quality improvement is the use of prescribed models for care with accreditation or certification processes that must be renewed regularly (Armstrong et al., 2019). These models, fostered in many jurisdictions, have been developed by advocates within the care home industry. Marketing these models has become an industry in itself, with a range of for-profit and charitable, non-profit organizations involved. Associated with the language of “culture change,” “emotion-centred care,” and similar buzzwords, these models include Eden, Greenhouse, Butterfly, and other brand names. Advocates for care home quality improvements often argue for one or another of these models, seeing them as a way to address the overly medicalized, institutional environments found in many jurisdictions.

Some governments have jumped onto the “model” bandwagon. For example, in 2013, the Norwegian federal government adopted the Joy-of-Life-Nursing-Home (JoLNH) model developed by a non-profit charitable foundation (Livsgledeforeldre, 2022). The JoLNH is a made-in-Norway model that builds on Norwegian strategies for health care services (André et al., 2021b). Its nine standards aim to create a meaningful everyday life for residents, emphasizing conditions that promote respect, well-being, cultural experiences, and intergenerational social and health-promoting activities. The nursing home must: (1) ensure all staff are familiar with the JoLNH philosophy and its implications; (2) facilitate cooperation with schools, kindergartens, and other organizations; (3) ensure all residents get outdoors to enjoy fresh air at least once a week; (4) facilitate contact with animals if residents desire it; (5) ensure that residents can maintain their hobbies and interests; (6) ensure residents experience meaningful musical and cultural stimuli; (7) facilitate a pleasant atmosphere during meals; (8) develop good practices for communicating with family and next of kin; and (9) ensure seasons and holidays are recognized and celebrated in daily routines.
Like many other models, JoLNH is implemented through a one-year certification process. Central to the model is the incorporation of a planning and assessment tool into the daily work of the nursing home. Its website declares:

Livsgledehjem is a system tool for nursing homes … aiming to stimulate each resident’s individual psychosocial needs. Cultural, spiritual and social needs are as important as the needs for medicine, nutrition and elementary care, and through Livsgledehjem, everyday life becomes more joyous and meaningful, even for the most fragile … By linking Livsgledehjem to the institution’s procedures and routines, the work becomes sustainable, regardless of who is at work. It encourages activities that are possible to carry out during regular workdays, without extra staffing. (Livsgledeforeldre, 2022, para. 4)

The model requires each care home to complete regular documentation and evaluation routines, and emphasizes a “sense of co-determination” (André et al., 2021b) among residents and staff. It encourages staff participation in developing each care home’s plan to meet the JoLNH standards. Independent academic studies evaluating this program implementation have been generally positive about the program’s effects. The studies showed improved resident quality of life (Rinnan et al., 2018; Haugan et al., 2021), and positive effects on staff’s overall work satisfaction (André et al., 2021b) and on work culture (André et al., 2021a). All but the study on work culture relied on qualitative interview methods with residents and staff to ascertain whether and how these quality improvements were met. The work culture quality assessment was determined with a relatively small sample multi-wave survey. No study included observations. In one assessment, staff reported that the program had helped them to be more consistent in attending to the needs of all residents, had encouraged more family and resident participation in activities, and had de-centred medicalization by requiring health care personnel to see residents as people, rather than as a diagnosis (André et al., 2021a).

Staff also reported that prior to JoLNH, they had been offering many of the activities and opportunities that the program required, but in a more variable, spontaneous way. The required documentation and the certification inspections supported them to be more consistent and planful in supporting residents’ quality of life and to include all residents, not just those they knew better. Implementing the model meant that they discovered more resident needs and added more nursing interventions to improve the residents’ well-being (André et al., 2020).

On the other hand, staff indicated that the documentation took staff time and attention, creating more task intensity and diverting them from direct resident care. Some care homes assigned JoLNH activities to designated staff, creating new divisions of labour that meant fewer shared responsibilities among the care team, thereby eroding teamwork. And with more activities going on at the
Making joy possible in care home policies and practices

care home in larger, shared spaces, staff were more spread out across the building, leaving some staff working alone to care for those residents who were unable or unwilling to leave the resident room “units.” Although the model helps ensure that joy is not dependent on individual relationships developed between staff and residents in Norwegian care homes, we question whether the model risks imposing an institutional homogeneity or does enough to facilitate the many kinds of relationships that cultivate joy for residents and staff.

Municipalities in Norway have a high level of autonomy in determining how they provide care, including whether to opt in to this program (Ågotnes, 2018). At the end of 2020, 110 of Norway’s 875 nursing homes were certified in this approach to care, about 12.6 percent of all homes. This dismal uptake suggests some problems in persuading municipalities to invest in the JoLNH approach.

What is clear from this example, however, is that it is possible to develop methods to plan, cultivate, and assess the conditions for joy in care homes. This measurement is primarily qualitative, as opposed to quantitative, but also looks for the presence of conditions that, in the context of Norwegian mainstream culture and understandings of what makes a good life, can produce the conditions for joy. Whether and how these conditions are perceived as universal or specific to a particular population and context are questions worthy of investigation (see Chapter 9).

HOW CAN JOY ADDRESS STRUCTURAL AND PROCESS CONDITIONS OF CARE?

So far, we have used joy as a critical starting point or angle to review some of the main types of care home quality improvement initiatives, noting the contradictions inherent in each approach.

Now we draw on our theoretical and empirical analyses of more than a decade of care home research to operationalize what we have identified as the conditions for joy. We conceptualize these conditions as those that promote and cultivate four kinds of basic human experiences. First, joy is possible in conditions where people can experience a sense of belonging. Second, joy relies on opportunities for purpose or meaning. Third, joy flourishes in conditions that promote sharing with others. And, fourth, joy emerges with opportunities to experience pleasure.

If we consider joy along these dimensions, as a kind of care home quality measure, it means we must examine the structural and process conditions of care, and not just the outcomes. Structural conditions are the material, political, economic, and social conditions – the ownership; financing; regulation; staffing levels, ratios, and education; and physical environments for care. The conditions for joy depend on these factors, and raise many questions, as our analysis has shown. Is there sufficient, and sufficiently qualified, staffing to
do the work, including developing relationships for care and teamwork? Do owners have so much political power and profit incentive that they help to shape required outcome measures into care minimums? Are buildings accessible, safe, and supportive for staff and resident purposes?

Process conditions are the practices of care, including formalized and informal guidelines, standards, and the relationships involved. A consideration of joy raises many questions about processes as well. Is time for relationship-building built into job descriptions, workflow, and staffing allocations? Are there standards for resident opportunities to engage in meaningful activities (rather than colouring books and other time-fillers)? Do guidelines for food service ensure food is tempting, culturally appropriate, and readily available? In our brief discussion of the dimensions of joy, we emphasize the relationship between care home structural and process conditions as indicators for joy.

Joy is Belonging: “I’ve always been a working stiff”

Belonging is the first aspect. In a care home, this means that all residents and the full range of staff – including nursing, dietary, housekeeping, laundry, and management – have opportunities to develop and maintain relationships with each other. The home’s cultural codes – or what is considered the ordinary way of doing things – are accessible to everyone. This does not mean that the cultural code is the same from nursing home to nursing home across a jurisdiction. Instead, it means that care home structural and process conditions support and encourage residents to know the staff and each other, while supporting staff to know the residents, regular visitors, and each other. This means, as only one benefit, that staff develop significant “cultural learning” not only through formal training, but through interpersonal relationships, including working time spent getting to know and listen to residents, their families, and other workers.

To support belonging, working time allocations and divisions of labour need consideration. In care homes that support belonging, staff have time to get to know residents and their families and make them welcome. Staff have time to learn about residents’ cultural, spiritual, and personal practices and preferences, including barriers they may face. They do not assume every resident wants their biological family around them, and they take time to check and understand who is important to each resident. Belonging also requires attention to residents’ and staff’s genders and gender identities, with the understanding that people express gender in different ways and gender expression is tightly tied to people’s sense of self. Belonging means being able to dress, groom, and be recognized as ourselves, which includes acknowledging our gender identity (Streeter et al., 2020). As one resident in British Columbia, Canada
explaining, “I’ve always been a working stiff. I don’t want staff to doll me up with a manicure and hairdo. I’m not that kind of woman.” A focus on belonging also means that “technological innovation” can stop focusing on robot care providers and electronic pets (Lanoix, 2019; Apostolova & Lanoix, 2022), and shift to developing easy-to-use simultaneous translation services. This use of technology can do a lot to support belonging in care homes where some workers and/or residents may have limited fluency in the language used in the home.

**Joy is Meaning: “That makes her day”**

Joy is also about meaning. All staff need to be able to find their work meaningful, and, in hundreds of interviews conducted in the jurisdictions included here, we confirmed that most care home workers want to interact meaningfully with residents and each other.

As one care aide in an Ontario nursing home put it,

> I pretty much know what all these people want and can pretty much – we have one lady, if you turn her sheets down, that makes her day. She’ll love you for it, so I make sure I do it, so that she’ll like me in that shift and it’ll make her happy and it makes everybody else happy.

But often workers experience structural and process conditions that prevent meaningful work. Care aides who had high resident care loads with many residents requiring extensive assistance were often too weary and overworked to experience meaning. We met maintenance staff who were told not to socialize with residents or other staff while doing their work, eroding opportunities for both belonging and meaning.

However, in some homes, we saw maintenance workers sitting with residents to take a coffee break and learned that spending time with residents was in their job descriptions. We saw a nurse doing data entry on an iPad while she sat chatting about local news with residents in a central sitting area. Another nurse had moved her office from the administrative wing to one of the floors to be able to be more present and interact with residents and staff. Housekeepers told us about how they contributed to the care team, both by chatting with residents as they worked, and by noticing small signs that residents might need more support with toileting, dressing, or other activities. Some workers told us that their sense of meaning and belonging was enhanced by having the discretion to set boundaries when they were out of emotional energy or had to complete a task that needed their full attention, and could choose to be unavailable for conversation with residents and co-workers at these times.
In our research, meaning-making opportunities were often limited or missing for residents. But we visited nursing homes where residents were finding meaning by using or developing their talents and skills, doing sculpture, pottery, painting, woodworking, music, and more. At one care home, in-house professional artists cultivated resident interests. As a resident told us, “I’d given up the idea I could learn something new. But I am and I’m not too bad at it.” Community art shows were held where residents’ work was prominently displayed and sold, with those in attendance enjoying wine and cheese as part of the event.

At another nursing home, some residents found meaning by running a morning coffee station, selling coffee to staff, residents, and visitors, with profits spent democratically by the residents’ council. These residents worked with a volunteer, an intellectually disabled adult from the community. The coffee business not only provided a sense of purpose for these residents, but also cultivated community within the care home, as residents and staff gathered to purchase a beverage and enjoy it at tables set up nearby. In these promising nursing homes, staff and residents had structural and process conditions to support their initiative to create and participate in life-affirming activities and relationships.

Joy is Sharing: “How can I help?”

This leads us to the third condition for joy. We must be able to share with others, including sharing stories, jokes, complaints, skills, tasks, and responsibilities. Opportunities to share with others must be cultivated but are often quite simple. At the coffee station, for example, residents worked with and mentored a community volunteer with an intellectual disability while the volunteer also assisted them, offered opportunities for sharing and meaning-making with collective opportunities to cultivate a sense of belonging for all. In a home in Ontario, Canada residents gather weekly to discuss current affairs at a “news and views” group. We witnessed how this group cultivated purpose and sharing as they collaborated with a volunteer to write a letter of concern about homeless seniors in their town.

In a home in Sweden, we saw shared daily rituals among residents and staff. Instead of smaller tables for three or four residents common in many jurisdictions, the 12 or so residents living in a care home unit ate together at a large family-style dining table, with staff first fixing plates of food to suit each residents’ tastes from the choices nicely arranged on a serving cart, then sitting down with residents to chat, help, and have a small portion of the food with them. Residents participated in conversation as much as they were able, and those who needed significant mealtime assistance received it.
Making joy possible in care home policies and practices

A personal dish of berries and cream was served, the enthusiasm at the table lifted appetites and a sense of sharing and pleasure.

In a UK dementia program, a supervisor responsible for social care told us about the importance of creating opportunities for residents to share in the work of the home as a form of meaning-making.

I can see that [a resident] is looking for something to do and sort of preventing that anxiety, right? Doing a sort of meaningful activity that you would do if you were living at home. You would be doing the washing up, doing the drying up ... we’ve had three ladies washing up and drying up and putting away at one stage, because we had lots of ladies that all wanted to be active and wanted to be helping. And they feel like they should be helping. They can see so many staff running around here and there and they think, “Oh how can I help? How can I help?”

This supervisor’s story points out that staff need opportunities to share as well. In some nursing homes, staff had opportunities to meet regularly to share their experiences and care knowledge, and to sort out how best to share the work. Some workers have discretion and time to check in with residents and other workers, to share some conversation or a joke, or make and share a cup of tea.

In a home in Nova Scotia, care home workers shared their own enjoyment of a “singles” paint night activity at a local bar by instituting and running a similar Friday “paint night” for residents at their care home. The program was a hit with residents, who enjoyed making art as a group, having some wine, and sharing a special Friday night activity with these engaged staff members. This group of residents and staff were clearly having fun, which leads us to consider the last aspect of our operationalization of joy.

Joy is Pleasure: “A new puzzle, it’s great!”

Pleasures are important to joy. We saw many care homes where simple pleasures were denied. Rules, restrictions, and poorly designed outdoor areas prevented residents from any opportunity to go outdoors unaccompanied, while staff had no time to take them. Snacks and beverages were not easily available between meals. Residents could access a bath or shower no more than twice a week.

In other care homes, we noted conditions that cultivate pleasure. In some homes, intimacy and consensual sexual activity were well supported (Daly & Braedley, 2017), with supplies, relationships, and privacy carefully and thoughtfully coordinated by staff. We also were in homes where treats such as wine and delicious, tempting food were shared frequently (Lowndes, Daly, & Armstrong, 2018). In one Texas home, ice cream sundaes on Sundays made for a pleasurable community ritual involving visiting families, including children,
and staff. Residents told us they looked forward to this ritual every week, while staff told us it was “a perk” for those working on weekends.

Organizing specific pleasures for residents can be a way to share as well. In one UK home, volunteers helped to organize moments of small pleasure for specific residents.

We’ve got a chap that loves to do puzzles but he only sort of does up to 100-piece puzzles and they’re quite tricky to find that aren’t for children ... So, we’ve got a couple of ladies that say, “Oh when I’m out and about I’ll have a look and see if there’s any ... .” And when he gets a new puzzle it’s great!

A recreational therapist in an Ontario home described how she supported residents with complex needs who were unable to leave their rooms. Her job description gave her discretion to do “one-to-one” programming. When she could not engage residents in conversation, she spent time with them, painting their nails, giving them a hand massage, or reading to them. The flexibility built into her job description was key to providing these small pleasures. “It’s not like we have a target list of how many to get done and how long to do them. It's just if we have time, it gets done.”

ADDRESSING QUALITY: BEGINNING AND ENDING WITH JOY

In considering joy as a socially determined need and a potential that is central to quality in care homes, we have unpacked the challenges of typical quality assurance processes, pointing out their strengths, limitations, and contradictions. Exploring joy as an angle from which to consider how care home quality is assessed and measured challenges assumptions embedded in many quality assurance processes, such as RAI-MDS, inspections, and audits.

We have also operationalized joy, illustrating the kinds of practices that support it, to spur thinking about the structural and process conditions that foster joy in care home environments. These conditions are those in which residents and workers (and families and volunteers, see Chapter 8) have the time and resources to devote to relationship-building, meaning-making, sharing, and enjoying.

In planning for a future for care homes in the shadow of the devastating effects of the Covid pandemic, welfare state policy shifts, labour force shortages in health and social care, and rapidly aging populations, it is easy to succumb to pessimism and to throw out the promise of collective living and caring in later life. We encourage all those concerned with care for older people to take a critical angle – to consider the future of care homes and the problems of quality by beginning with joy.
NOTES

1. This definition differs from conceptions of joy as a euphoric, transcendent sensation.

2. For a list of jurisdictions currently using this tool, see https://interrai.org/about-interrai/#/interrai-worldwide

3. Some researchers are testing other measures to assess quality of life, using quantitative, comparable measurement tools, but these rely on surveys administered to cognitively capable residents (Kehyayan et al., 2016).

4. See https://livsgledeforeldre.no/livsglede-for-eldre-engelsk/ for details of this program and the charitable foundation.


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**Index**

<table>
<thead>
<tr>
<th>2SLGBTQIA+</th>
<th>120</th>
</tr>
</thead>
<tbody>
<tr>
<td>2SLGBTQIA+ residents</td>
<td>117, 124</td>
</tr>
<tr>
<td>access</td>
<td>101</td>
</tr>
<tr>
<td>accessibility</td>
<td>11</td>
</tr>
<tr>
<td>accountability</td>
<td>5, 7, 28, 137, 140–2, 144–7, 149</td>
</tr>
<tr>
<td>Adecco</td>
<td>25–6</td>
</tr>
<tr>
<td>ÄDEL reform</td>
<td>121</td>
</tr>
<tr>
<td>advocacy</td>
<td>107, 109</td>
</tr>
<tr>
<td>Affordable Care Act</td>
<td>29</td>
</tr>
<tr>
<td>AgeCare</td>
<td>23</td>
</tr>
<tr>
<td>agency staff</td>
<td>9</td>
</tr>
<tr>
<td>aging in place</td>
<td>4, 50</td>
</tr>
<tr>
<td>Anderson*</td>
<td>78</td>
</tr>
<tr>
<td>Armstrong, Hugh</td>
<td>137, 140, 149, 151</td>
</tr>
<tr>
<td>Armstrong, Pat</td>
<td>137–8, 149, 151</td>
</tr>
<tr>
<td>Banerjee, Albert</td>
<td>148</td>
</tr>
<tr>
<td>bathing</td>
<td>39–40</td>
</tr>
<tr>
<td>body care</td>
<td>39</td>
</tr>
<tr>
<td>bottom-up accountability</td>
<td>140</td>
</tr>
<tr>
<td>boundaries</td>
<td>68, 71, 74–5, 78</td>
</tr>
<tr>
<td>boundary maintenance</td>
<td>74</td>
</tr>
<tr>
<td>boundary work</td>
<td>71–4, 77–9</td>
</tr>
<tr>
<td>Brius</td>
<td>29</td>
</tr>
<tr>
<td>Brodin</td>
<td>123</td>
</tr>
<tr>
<td>buildings</td>
<td>83, 88, 91</td>
</tr>
<tr>
<td>Canada</td>
<td>1, 4, 19–22, 24, 26–8, 37–42, 50–2, 54, 57–9, 90, 99, 100, 118, 120–5, 130–1, 137, 152, 156</td>
</tr>
<tr>
<td>Canada Pension Plan Investment Board (CPPIB)</td>
<td>22</td>
</tr>
<tr>
<td>Canadian care homes</td>
<td>86</td>
</tr>
<tr>
<td>Canadian home</td>
<td>39</td>
</tr>
<tr>
<td>Canadian nursing homes</td>
<td>19</td>
</tr>
<tr>
<td>Canadian “points” immigration system</td>
<td>119</td>
</tr>
<tr>
<td>CanAge</td>
<td>29</td>
</tr>
<tr>
<td>Cantonese</td>
<td>127</td>
</tr>
<tr>
<td>care aide</td>
<td>85</td>
</tr>
<tr>
<td>care aides</td>
<td>91</td>
</tr>
<tr>
<td>care arrangements</td>
<td>122</td>
</tr>
<tr>
<td>care home</td>
<td>82–4, 86–96, 151–64</td>
</tr>
<tr>
<td>care home labour shortages</td>
<td>6</td>
</tr>
<tr>
<td>care home physical environments</td>
<td>89</td>
</tr>
<tr>
<td>care homes</td>
<td>1–2, 5, 13, 63, 87–8, 90, 96, 158, 164</td>
</tr>
<tr>
<td>Carema</td>
<td>25</td>
</tr>
<tr>
<td>care quality</td>
<td>109</td>
</tr>
<tr>
<td>care, relationship</td>
<td>92</td>
</tr>
<tr>
<td>care relationships</td>
<td>34–5, 45, 62</td>
</tr>
<tr>
<td>care services</td>
<td>100</td>
</tr>
<tr>
<td>Centre for Health and the Public Interest (CHPI)</td>
<td>22</td>
</tr>
<tr>
<td>Chartwell</td>
<td>24</td>
</tr>
<tr>
<td>Chinese-Canadian community</td>
<td>127</td>
</tr>
<tr>
<td>Chinese nursing homes</td>
<td>127</td>
</tr>
<tr>
<td>cleaning</td>
<td>95</td>
</tr>
<tr>
<td>cleanliness</td>
<td>38</td>
</tr>
<tr>
<td>climate change</td>
<td>93</td>
</tr>
<tr>
<td>collaboration</td>
<td>149</td>
</tr>
<tr>
<td>collective bargaining</td>
<td>57</td>
</tr>
<tr>
<td>communication</td>
<td>106, 109</td>
</tr>
<tr>
<td>competitive bidding</td>
<td>4</td>
</tr>
<tr>
<td>compliance</td>
<td>144, 148–9, 155</td>
</tr>
<tr>
<td>congregate care</td>
<td>40</td>
</tr>
<tr>
<td>Covid-19</td>
<td>1, 3, 7–15, 17, 19, 34, 55, 67–8, 70–1, 73, 75, 99–109, 111–12</td>
</tr>
<tr>
<td>Covid-19 pandemic</td>
<td>26</td>
</tr>
<tr>
<td>Covid lessons</td>
<td>7–8</td>
</tr>
<tr>
<td>cultural change models</td>
<td>7</td>
</tr>
<tr>
<td>cultural change movement</td>
<td>5</td>
</tr>
<tr>
<td>cultural learning</td>
<td>160</td>
</tr>
<tr>
<td>culturally safer care</td>
<td>127, 129</td>
</tr>
<tr>
<td>culturally safer nursing home care</td>
<td>129</td>
</tr>
<tr>
<td>culturally safe work</td>
<td>129</td>
</tr>
<tr>
<td>culturally specific homes</td>
<td>124, 126–7, 129</td>
</tr>
<tr>
<td>culturally specific nursing homes</td>
<td>126–7, 131</td>
</tr>
<tr>
<td>cultural safety</td>
<td>62</td>
</tr>
</tbody>
</table>
meaningful activities 94
meaning-making 162–3
Medicaid 88
medical care 36–7
medical indicators 37
medicalization 158
metaphor 151
Mol, Annemarie 26
multicultural approach 128, 130
multiculturalism 118, 120
neoliberalism 8
neoliberal strategies 4
NH 72, 77
NHs 68–72, 74–6, 78
NH staff 72
NHs workforce 69
North America 5
North American regulatory systems 139
Norway 1, 4–7, 21, 24–6, 36–7, 40–1, 44, 50–1, 53–5, 57, 61, 69, 71, 93, 147, 159
Norwegian Corona Commission 68, 71
Norwegian home 39
Norwegian nursing home 92
Nova Scotia 95, 163
Nova Scotia home 92–3
nursing home 50–2, 54, 57–9, 160
nursing home care 7, 131
nursing home funding 25
nursing home inspection and licensing Act, 1966 142
nursing home (NH) 67
nursing home ownership 29
nursing home policy 3
nursing staff 73
Ontario 54, 91, 99, 101–3, 105, 109, 111–12, 153, 156, 164
Ontario care home 93
Ontario nursing home 128, 161
operation 21, 24, 27
ORPEA 22
Oslo nursing home 25
outsourcing 5
outsourcing management services 9
ownership 20, 21, 24, 27, 122, 138, 144
pandemic 83, 87, 96, 106, 111
part-time employment 61
part-time staff 54
pay and benefits 57
pension funds 27
Personal Protective Equipment (PPE) 7, 35, 59, 84, 86, 104
personal support worker (PSW) 141
physical design analysis 82
physical environments 82–3, 86–96
pleasures 163–4
population aging 3, 19
population heterogeneity 131
population homogeneity 121
privacy 41
private equity (PE) 19, 20–1, 29, 144
Private Financing Initiatives (PFIs) 27, 29
private homes 13
private investor acquisition 144
privatization 152
public investment 70
public-private partnerships 27
Public Sector Pension Investment Board (PSPIB) 22
quality 151–2, 164
addressing 164
quality assurance 152, 156, 164
quality indicators 12
quality of care 138, 144, 155
quality of life 155
racialized care worker 125
racialized staff 56
racism 130
real estate investment trusts (REITs) 19, 20, 21, 23, 27, 28, 29, 30, 145
Registered Nurse (RN) 25, 51, 77, 101
Registered Practical Nurses (RPNs) 51
regular training 10
regulation 138, 140, 142–3, 147, 149, 155, 159
relationships 92–3
Resident Assessment Instrument
– Minimum Data Set (RAI-MDS) 141, 153–5
residents 117–8, 121–2, 124–32
retirement homes 19
Revera 22–3, 27–9
risk 36, 38, 41
risk avoidance 35–6, 41
risk tolerance 35–6
Ronald, L. A. 20

Sami Truth Commission 119
self-care 10
self-isolation 76
sensory pleasures 94
sharing 162
Siverskog, A. 123
skilled work 79
skill requirements 10
skills 62
skills training 62
Skyline Healthcare 144
social care 40
social care integral 112
social citizenship 142
social exchange 40
social inequalities 52
Social Services Act 122
social welfare regimes 2
spiritual practice 94
staffing levels 53–5, 58–9, 61, 87, 103, 144
staffing shortages 87
staffing standards 144
Stockholm municipality 104
Stockholm nursing home 25
Storm, P. 130
structural supports 34

Struthers, James 142
Struthers, Jim 137–8, 148
Sweden 1, 4–7, 14, 21, 24–6, 37, 38–9, 41–2, 44, 50–5, 57, 93, 95–6, 99, 100–3, 105, 109–11, 118, 120, 122, 124–5, 162
Swedish care homes 121
Swedish Corona Commission 7, 55, 62
Swedish home 39, 94
Swedish nursing homes 106
Swedish welfare state 119
teamwork 58, 62
transparency 23, 29, 30, 144–6
trust 111, 149
tsunami 4

United Kingdom (UK) 1, 4–5, 22–4, 26, 28, 41–2, 94–5, 163–4
United States (US) 1, 4, 21, 24, 26, 28–9, 41–2, 137, 143, 152
universalism 121
welfare programs 4
welfare state 3
well-being 105–6, 158
workers 120–1, 124–5, 128–32, 141, 161, 163
workers’ health risks 55
working conditions 50, 53–5, 59–63
work organization 58
workspaces 58
World Health Organization 7