

The Thin Blue Line

Long-Term Care as an Indicator of Equity in Welfare States

PAT ARMSTRONG, HUGH ARMSTRONG AND TAMARA DALY

Dans ce papier, nous affirment que les soins de longue durée en établissement, en particulier pour les personnes âgées, peut être utilisé comme un indicateur de l'équité et donc de la mesure dans laquelle il y a un état consacré au bien-être de ses citoyens. Par équité, nous entendons traiter à la fois ceux qui fournissent et ceux qui nécessitent des soins de façons qui sont appropriés à leurs besoins et qui maintiennent leur dignité, ainsi que leurs capacités.

In this paper we argue that long-term residential care, especially for the elderly, can be used as an indicator of equity and thus, of the extent to which there is a state devoted to the welfare of its citizens. By equity, we mean treating both those who provide and those who require care in ways that are appropriate for their needs and that maintain their dignity, as well as their capacities.

There has been considerable debate about whether welfare states do, or ever did, promote equity (Blake, Bryden and Strain; Dobrowolsky; Lewis and Surrender; O'Connor, Orloff and Shaver; Sainsbury). Indeed, there is debate about whether or not we can even talk about welfare states anymore in such terms. Various methods have been developed to classify and assess welfare states, with equity

used as one variable among others (Anand, Peter and Sen; McGill Institute for Health and Social Policy; van Doorslaer). Such methods operate at different levels of abstraction or scales, often in ways that either makes comparisons difficult or that oversimplify differences within and among states. At the same time, the notion of accountability has gained widespread popularity in state circles, with accountability often thought in terms of indicators that can be used as the basis for decision-making by the general population, as well as by states. Intended as a means for monitoring, evaluating, and comparing, indicators can be used to assess equity (Standing). Here we propose that the very concrete case of long-term care, especially for the elderly, can be used as an overall indicator of equity, and thus, of the extent to which there is a state devoted to the welfare of its citizens. By equity, we mean treating both those who provide and those who require care in ways that are appropriate for their needs and that maintain their dignity, as well as their capacities.

In this paper, we use specific examples from long-term care in Canada to develop our argument for focusing on long-term facility care for the elderly. To do so, we draw on primary research we have conducted over the years.

The first research project, in 2002, was based on group interviews in Ontario and British Columbia with 40 workers in long-term care. These interviews, which lasted between two and four hours, were followed by a two-hour discussion with another group of 40 workers, who were asked to comment on our initial findings from the interviews and to identify gaps or challenge interpretations (see Armstrong, Jansen, et al.). The second study, undertaken two years later, involved a sample survey of Canadian Union of Public Employee (CUPE) members employed in Ontario long-term residential care. With responses from nearly a thousand workers, we were able to develop an analysis based on their answers to both open-ended questions and to ones that involved choices among a five-point scale (Armstrong and Daly). Two years later we combined survey and group interview techniques, and extended our focus beyond Ontario to also include Manitoba and New Brunswick, as well as four Scandinavian countries (Armstrong et al. 2009). Nearly a thousand Canadian workers filled in the surveys, many writing comments in the margins in addition to responding to closed and open-ended questions. Nine Canadian focus groups were organized to ask other workers to assess our analysis

and add their own experiences. All three studies were undertaken in cooperation with unions, although the analyses were ours alone. While a growing number of those requiring long-term care remain outside facilities and an increasing number of those in long-term care facilities are not elderly, we restrict our attention here to the elderly in facility care.

We begin this chapter by setting out our framework and explaining why long-term facility care for the elderly is an appropriate indicator of equity in welfare states as well as a useful basis for comparison among states. We then turn to an exploration of some critical issues for those who work in long-term care, suggesting factors that may be used in the development of a set or suite of indicators that become the basis for using long-term residential care as an overall indicator in assessing equity. Our contentions are that the health of these workers is shaped by their conditions of work, and that both these conditions and workers' health set the context for care. We then turn to issues of care for residents, suggesting some further additions to our suite of indicators for assessing equity. And, finally, we look at the ownership and payment structures, both of which we argue are factors in equity and should be included in any assessment. Like the conditions for providers and residents, those for ownership are established to a large extent by the state operating at the international, national and local level and thus reflect the state's approach to care.

Welfare States, Equity and Indicators

Our proposal for using long-term facility care for the elderly as an indicator of equity is based on our understanding of roles states play, of equity and of democratic participation. States, from our perspective, operate in at least five ways that are central to our analysis here and they shape actions on multiple scales. One is through international agreements and activities that shape and reflect

conditions, relations and ideas within countries. Another is the legislation which sets the context for activities within states while a third is the regulation and monitoring of these activities. States also provide services and infrastructures, directly and indirectly. And finally, they establish the conditions for democratic participation in decision-making in all areas. Failure to act in any of these fields can be as important as explicit or visible action. Like Esping-Andersen, we think it is useful to compare welfare states in order to understand not only differences but also ways of enhancing state development. However, we find it useful to explore these comparisons through concrete practices. And, like Nancy Christie, we think it is important to engender the state through the examination of such practices. All five of these state influences are evident in long-term care for the elderly, as we show in subsequent sections. Moreover, long-term care is highly and obviously gendered. For the most part, it is care for women by women. In addition, many of those who provide care are from immigrant and/or racialized communities (Armstrong et al. 2009).

Our central assumption is that equity must be the primary objective of all genuine welfare states. Equity is about carrying out all state activities in ways that promote appropriate responses to different needs and create conditions that allow individuals as well as groups to participate to the extent of their abilities. Such conditions include those that allow people to live with dignity and respect. Like Sonia Corrêa and Rosalind Petchesky (8), we understand equity as involving four principles. The first is what they call "bodily integrity, or the right to dignity and respect for one's physical body and to be free from abuses and assaults." The second is "personhood," by which they mean "the right to self-determination and respect in one's decisions." The third is equality in access to services and social resources, not only among women and men but also among women and among

men in different social locations and relations. The final principle has to do with "diversity, or the right to be respected in one's group affiliations and cultural differences, in so far as they are freely chosen." We would add that such affiliations must also conform to notions of human rights and the dignity of others. Long-term care for the elderly is a service where questions of bodily integrity, personhood, equality in access and services, and diversity all come into play.

By indicators, we mean some qualitative or quantitative measure that can serve as a barometer. An indicator is a means of revealing a broad range of issues or developments through a few selective factors. We focus on indicators in part because they have become so popular in welfare states, especially in the area of health care services. For example, when in 2004 then Prime Minister Paul Martin agreed to huge financial transfers to provinces and territories for health services, his sole condition was that they develop some indicators on health and care (Martin). This emphasis on indicators reflects the importance they have gained in the management of health services. But they have also been promoted as a means of allowing people to choose their health services, based on knowledge gained from indicators and as a way to ensure accountability to both governments and citizens. Appropriate indicators can serve as a tool to encourage democratic decision-making by sharing information in a manner that allows us all to assess policies in practice.

However, indicators are not merely technical means of measurement that are to be created by experts in the field. The kinds of indicators that are developed and the ways they are used involve significant and values-based decisions that reflect and shape current power relations. It is because indicators are so widely used (albeit often as a means to convince rather than as a means to assess) and because they could enhance democratic, collective decision-making (even though they are often intended to focus on individual choice), that we argue for

long-term care for the elderly as an indicator of equity in welfare states. Because the conditions of work are the conditions for care, we suggest indicators that capture the conditions with the most obvious impact on care. For these reasons, we also propose the development of a suite of specific indicators within long-term care that together constitute an indicator of equity.

Commission on the Future of Health Care in Canada (Romanow) never even considered such care.

Yet there is no necessary reason why facility care should fit this characterization or be defined as the last resort for failures. Facility care can provide a collective and attractive alternative to the isolation of individual homes. It can offer shared facilities, designed to accommodate physical and mental

capital expenditures, although fees can be charged for what is defined as accommodation and extras. What is defined as an extra may vary. The government also regulates the fees that can be charged for basic (\$1,480.99 monthly), semi-private (\$1,724.32) and private rooms (\$2,028.49), requiring that all facilities reserve at least 40 percent of beds for basic rooms that are charged at the lowest rate.¹

Equity is about carrying out all state activities in ways that promote appropriate responses to different needs and create conditions that allow individuals as well as groups to participate to the extent of their abilities. Such conditions include those that allow people to live with dignity and respect.

Why Long-Term Facility Care for the Elderly?

The choice of such care may be surprising, given that facilities are increasingly out of favour, if indeed they were ever seen as a good option. As Nancy Guberman (77) puts it, such institutional care is frequently characterized as cold, unfeeling, regimented and without choices, especially compared to care at home. Although there are variations among countries in attitudes towards institutional care, long-term facility care is defined most often as the last, and final, resort. The recent report from the Organisation for Economic Cooperation and Development (OECD), for example, acknowledges the need for residential care but begins the introduction and conclusion with family carers and stresses paid home care over facility care (OECD). In most high-income countries, it is very difficult to get into such facilities unless no other services are available and the health problems are complex. Only death takes most people out of residential care, although U.S. research indicates that a majority live in them for at least two years (Kelly et al.). Like death in our medicalized world, it has become an indication of failure by families to provide care or by health care services to cure. Perhaps this is why the federal

capacities, and do so in ways that are more sophisticated and less expensive than is possible in equipping individual homes. It can organize a place where care is provided by a team of decently paid providers whose complementary skills are combined to offer appropriate, respectful care. It can be designed to allow democratic participation in decision-making by residents and their families as well as flexible scheduling that suit individual needs and preferences in ways that respect diversity. It is precisely because it is possible to construct such facilities that they can be used as an indicator of equity in a welfare state.

In Ontario, for example, this means looking at the municipal homes usually called homes for the aged, at charitable homes, many of which have a religious affiliation, and at nursing homes, most of which are for-profit enterprises. Until recently, each kind of home was covered by its own legislation that detailed standards in areas such as the physical environment, food and some aspects of care. The *Long-Term Care Homes Act, 2006* combines all three kinds of facilities under the same act, in part because now all three receive much of the same subsidies from the provincial government and care for a similar range of residents. The subsidies cover most “nursing” care and some

While the *Canada Health Act* prohibits fees for hospital and medical care, Ontario does not define these facilities as hospitals and does not define the care as mainly medical. There are also provisions for government monitoring and inspection of facilities to ensure conformity with long-term care and other legislation. Private residential care facilities, usually called retirement homes, are proliferating partly in response to the limited access to long-term care facilities. These retirement homes are not regulated by facility legislation, are not directly subsidized by the public purse, and are not regularly monitored through inspections or other means. While the federal government plays little direct role in legislating, regulating, monitoring or providing long-term care services, it does influence these facilities through the role it plays at the international level and through the ways it shapes ideas about responsibility, ownership, and care.

Once, almost all of the residents in these Ontario facilities were elderly and many were simply frail and unable to live on their own. As a provider affectionately explained in a focus group on the changing conditions for care, “They were little old ladies; they were intermediate care grannies” (Armstrong, Jansen,

et al. 187). Now, “They’re either dementia patients or chronic care. We rarely get what we call a higher functioning resident. Even our higher functioning residents are what at one time we may have called the low chronic care residents.” Moreover, the closure of many chronic care and psychiatric hospitals has meant that some of these former patients have been transferred into long-term care facilities. Although it is still the case that the majority of residents are elderly, the addition of these younger and often physically stronger people with severe disabilities alters the conditions for work and for care by making it more difficult to reconcile demands and interests. These reforms also mean there are many more men in the facilities, men who are stronger and often heavier than the women who still form the majority of residents. These changing populations and conditions justify a renewed emphasis on examining care for the elderly in these facilities.

The elderly who reside in them and face these changing conditions are among the most vulnerable citizens in all countries. While they have made significant contributions to paid work, their communities and to family life or in the words of one Ontario long-term care worker, “people who have done so much for their country all their lives,” most are no longer able to do so. Yet, “Being old doesn’t mean you don’t have feelings anymore or don’t get lonely” (Armstrong and Daly 15). This is not a recoverable labour force, which may help explain why some of them were recently described by a member of the Ontario legislature—and former health minister—as “Ontario’s forgotten people” (Witmer). It is easier to argue for investment in children precisely because they will be the labour force (Williams). Moreover, the majority of the residents are female. This gender distribution may also contribute to the paucity of research and of public attention to their care. It certainly helps account for their limited financial resources, given that women are more likely than men to

be poor in their old age and tend to outlive their male partners.

At the same time, the number of elderly is growing significantly and this trend will continue for the next couple of decades not only in Canada but also abroad. By 2026, it is estimated that one in five Canadians will be over 65 years of age (Statistics Canada 1). The majority will still be female. However, this elderly population will be much more diverse in the future. According to Statistics Canada, “the characteristics of younger seniors aged 65 to 74 differ from those of their counterparts aged 85 and over, in many cases dramatically. This is especially true with respect to health, cultural origins, financial situations, living arrangements and so on” (1). The proportion that is foreign-born and from racialized groups in particular will increase, and so will the number with financial resources, both because more of the women have had paid jobs and because more of them are eligible for pensions. While these figures are for Canada as a whole, the patterns in many other jurisdictions are similar (OECD).

What has often been called the aging of our population has received a lot of attention in policy and media circles, especially in terms of an assumed growth in public expenditures on health services. Even if a smaller proportion of the future elderly need long-term care compared to the present, there will still be an increase in demand for care. This concern over a dramatic increase in the number of elderly has not been matched by a dramatic increase in research on their care or in public investment to address their needs. For example, patient safety in long-term care has not been major focus of research and policy, especially compared to hospitals where there is an expectation of cure (Castle et al.). As a study by the Organisation for Economic Cooperation and Development (Huber) points out, estimates and profiles for long-term care are not well-developed compared to other areas of public spending. However, the evidence available indicates

that the share of public health care spending devoted to long-term care has been going down in Canada and Australia, to take just two examples (Huber 12).

In short, we are arguing that the elderly in long-term care facilities are among the most vulnerable and neglected populations. Moreover, their numbers are growing or at least would grow if long-term care was available to the elderly in need of care. Equity is a concern for many reasons, including the fees charged for care, the high proportion of women and the increasing diversity among the elderly population. The conditions of this care are set by states and, in turn, shape the extent to which the facilities promote bodily integrity, personhood, equality in terms of access to services and resources, and diversity. How welfare states care for their most vulnerable populations can be used as an important indicator of its commitment to equity, one that offers a very concrete means of assessing this commitment. In the next section, we suggest some specific ways for developing this assessment.

Care for Residents

There are, of course, many ways of assessing care for the elderly. What we consider here are three which we think can serve as the canaries in the mine shaft, indicators of the extent to which appropriate care can be provided in a manner that allows the elderly to retain their dignity and their personhood while respecting diversity and ensuring access. They are based on the assumption that the conditions of work are the conditions for care (Armstrong et al. 2009). The three contribute to the suite of indicators that together provide an indicator of equity.

Our first specific indicator is a common one: namely, staffing levels. The level and mix of staff are critical factors in setting the conditions for care. Indeed, the province recognized the importance of staffing years ago by requiring that at least one Regis-

tered Nurse be on each shift and by setting a minimum of 2.25 hours per resident as the care standard. Yet, in 1996, just as resident care needs increased with health reforms and demographic changes, the Conservative government removed both of these requirements. Those we interviewed reported that, in the wake of these changes, care providers were often looking after twice as

support necessary for good health. This, respondents reported, was the task most frequently sacrificed as workers faced a doubling and even tripling of their resident load. As one respondent put it (Armstrong and Daly 19), low staff levels mean “We have no time to talk to residents and do the little things that count. We have not social time due to lack of staff.”

baths a week as a minimum standard. However, it has not introduced a new minimum standard for care hours, even though the province of Alberta, for instance, is working towards 3.6 hours of care daily and even though a 2005 Coroner’s Jury recommended the reintroduction of minimum staffing standards after two residents died in part as a result of low staffing levels. Most of those we surveyed thought

Equity is a concern for many reasons, including the fees charged for care, the high proportion of women and the increasing diversity among the elderly population. The conditions of this care are set by states and shape the extent to which the facilities promote bodily integrity, personhood, equality in terms of access to services and resources, and diversity.

many residents as before, with each of those residents requiring more care (Armstrong, Jansen, et al.). There were never standards for the other workers in long-term care, such as those who clean and work in the kitchens, even though their labour is essential to the health of residents and to the work of those defined as caregivers (Armstrong, Armstrong and Scott-Dixon).

In her report to the Ontario Ministry of Health and Long-Term Care, Monique Smith identified staff shortages as a central issue. Such shortages have critical consequences for the quality of care residents receive. In our subsequent survey of long-term care workers (Armstrong and Daly 24), respondents reported that such obviously essential tasks as turning people in bed, changing bed linens and cleaning bathrooms are left undone 20 percent of the time, while bathing is left undone almost 20 percent of the time. They said tasks essential to maintaining health, independence and dignity, such as walking and exercising, were left undone half the time and foot care 40 percent of the time. Without exercise, foot care and turning, residents can quickly lose any capacities that remain. These tasks would be easy to record and measure.

Less obvious, and more difficult to measure, is the social and emotional

The issue is not only with the number of people defined as providing care, such as Registered Nurses (PSWs), Licensed Practical Nurses (LPNs) and Personal Support Workers (PSWs). Often the first to go with cutbacks are those in the kitchen and laundry. As a result, work is transferred to those who remain, with PSWs “required to serve dining rooms at meal times and put away all the residents’ laundry and linen daily” (Armstrong and Daly 18).

Low staff levels mean pressure to focus on the most essential tasks and to treat everyone in the same manner, regardless of preference and need. Yet it is possible to attend to individual bodies and minds, as some of the workers we have interviewed attest. One spoke about a woman who is allergic to soap, “so I strip her bed and wash her sheets and fold them and put them back” while another in the same group said she cares for a woman who “likes a certain kind of cereal. I go and get it for them” A third reads to a blind woman, but does so after her shift, and pay, are over.

Standards for staffing are a necessary, if not sufficient condition, for equity and provide one kind of indicator. Ontario has reinstated the requirement to have an RN on each shift, introduced regular, unannounced inspections and set two

many of the government’s written standards for the kind of care required were fine, but low staffing levels mean these standards cannot be met. Nearly one in five said that more than half the time they were unable to complete tasks in a manner that complies with the standards and another 14 percent said they were never able to do so (Armstrong and Daly 23). And these responses do not consider the less tangible tasks such as emotional support. Echoing our interviews of three years earlier, a worker wrote in the following on her 2007 survey return (Armstrong, Armstrong and Daly): “All tasks require more time than I have. We are short most of the time and have prioritized our tasks so a lot of emotional and assisted things don’t get done,” for example, “if I have a resident who can do some of their own ADLs [Activities of Daily Living], I don’t have the time to allow for this because it would take the resident 20 mins. More of my time with them to allow them to do it.” Another wrote that they need time for “assessment of residents, finding out how they are feeling—not only emotional but physically and mentally.” This kind of time is even missing from the written standards and is usually impossible to carry out in practice.

So an indicator that simply looked at standards would not be sufficient

to assess equity defined in terms of bodily integrity and personhood. As one worker succinctly put it in our 2007 survey:

Burn out is coming from increasingly complex care residents without the resources to meet the needs of individual residents and staff, while government increase standards without providing

personal care envelope in long-term care facilities. The money could be used for staff, education and supplies. A government-commissioned study of how the money was spent found that, on average, homes allocated 13.4 percent on incontinence supplies (Sigma-3 Policy Research 3). This seems like a lot of money for diapers, and raises questions about expenditure on soaking up inconti-

policy and the acknowledgement by the Acting Premier that this does not seem like treatment with dignity and respect, the policy remains in place at many facilities. Listen to these workers, in a group interview held earlier that year:

As far as toileting goes, I think that as workers we feel we're doing the best of our ability to

“Workers are not allowed to change the undergarments of incontinent residents until they turn blue, even if they know that an incontinent senior is sitting in their own urine or feces for hours at a time. If it’s 20 percent or 50 percent or 75 percent full, it can’t be changed—only when it’s 80 percent full, when it turns blue.”

the money to hire the staff to meet the needs. It has become a bad joke.

It would require not only standards for minimum staffing and more accurate reporting of actual services provided. Inspections may not be enough, given that “people and supplies just fall out of the sky” for inspections. It’s “magic” on inspection days although there are “never” enough on other days. Thus, capturing staff levels would also require more qualitative assessments. Such qualitative assessments would include interviews with the workers and residents in order to draw on their experiences of how standards work in practice rather than on paper. Moreover, the standards for minimum staffing should include not only those who provide care, most of whom are personal care workers, but also those who clean and do dietary work because cutbacks in these female-dominated jobs mean greater workloads for those most directly involved in care.

This takes us to our second specific indicator, one more focused on the actual care provided. Our indicator has to do with the use of what official documents call incontinence pads and most providers call diapers. In 2002, the Ontario government increased funding for the nursing and

nence rather than on preventing it through toileting and other forms of care. It also raises question about bodily integrity, personhood and thus equity.

In question period at the Ontario Legislature, the leader of the New Democratic Party used the release of a Coroner’s report to ask the Acting Premier about the ways diapers are used in long-term care and to illustrate his point with an actual diaper:

It’s an undergarment for incontinent seniors. When it’s 80 percent full, it turns blue. Workers at Extendicare nursing home in St. Catharines are not allowed to change the undergarments of incontinent residents until they turn blue, even if they know that an incontinent senior is sitting in their own urine or feces for hours at a time. If it’s 20 percent or 50 percent or 75 percent full, it can’t be changed—only when it’s 80 percent full, when it turns blue. (Hampton 17)

Imagine yourself in that situation. Imagine the embarrassment, the humiliation. Imagine being dependent upon someone to help you, but they won’t help you because the rules don’t allow them to.

In spite of the exposure of this

do it. I don’t know about anybody else, but do you know that in the last year or so they have really, really pushed the use of incontinent products and that is wrong because what I’m seeing, and I mean I’ve worked in the facility for 27 years so I’ve seen the changes from using, you know, cloth material as diapers to, you know, disposable diapers to Depends that they’ve got now. And what they’re using now they’re limiting us to how many Depends that we can put on these residents.... (Armstrong, Armstrong and Daly)

Yeah, we’re not allowed to change these residents unless they’re 75 percent.

Don’t get us wrong cause we’re not saying that they’re being toileted on a regular basis cause that’s so not what’s happening. We’re caring for them the best we can but they’re sitting in diapers that are saturated ‘cause they say that they hold all this liquid....

In that product and they don’t.

Yeah, and they’re limiting us. And I’m telling you, they’re monitoring it....

They have diaper police.

There's only so many that are sent to each unit. It's one per shift. It's unbelievable.

And management will go round and they will look in all the closets and all the drawers and they will pull all the hidden stuff out. I mean the girls hide it all over.

We have to steal them [laughter].

Seriously. You want to take care of your residents properly. If they're wet, you want to change them. If I've got a baby sitting in front of me, that baby I feel dampness, we're likely to change them. With our elderly we say, "At 75 percent, we change them."

It's absolutely true what they're saying cause we have the same... There's not the nursing staff to toilet every hour like they want and what they need.... We do the best we can do in the time that we're given....

And the products that we're given to do it with.

It's not that we feel good about it either.

No.

In these diapers, "[t]here's a line at the top up here. Once that line changes colour, they're 75 percent." The thin blue line in the title of this paper refers to the line that must be reached for incontinence pads to be changed, another kind of indicator. Our research suggests that not all homes have this policy and not all workers follow it, but it does suggest a means of assessing equity. Such an assessment would have to consider the entire policy on diaper use, including organizational efforts to maintain continence, and support for resident's own efforts to remain comfortable and dignified. With the thin blue line, there is little room for

any response to individual needs or for the development of culturally appropriate responses.

A third specific indicator we suggest is the use of drugs. Research indicates significant variation in drug use among facilities. A study of Ontario facilities (Rochon et al., 2007) found that those with high prescribing rates for antipsychotic drugs were more likely to prescribe such drugs to patients who showed no signs of needing them in comparison to facilities with low overall prescribing rates. Earlier research (Lane et al.) indicated, however, that residents in long-term care facilities are less likely than those treated at home to be prescribed inappropriate drugs in the 'always avoid' or 'rarely indicated' categories, which the authors suggest is related to the use of clinical pharmacy services in these facilities. Such variations raise important questions about the extent to which states support, or at least tolerate, the use of drugs as a substitute for care and other inappropriate uses for drugs in the elderly. Equally important, we know very little about variations in patterns of drug use among patients related to class, gender, and racialization. Indeed, we are only beginning to get research on drug effectiveness as it relates to class, but little on gender, and even less research on the impact for racialized groups (Rochon et al. 2004)

This use, in turn, is related to the earlier question of staffing and time. Without time for "assisting with exercise and social care," without "being able to spend more quality time with the patients," as worker after worker said in our most recent survey (Armstrong, Armstrong and Daly), drugs may well become the alternative form of care.

The existing research thus suggests an indicator that would assess the use of drugs in relation to diagnosis. However, what is also required is more research on both appropriate diagnosis for elderly from different social locations and more research on the impact of drugs for different groups of the elderly. Without invest-

ment in such research, the indicator will remain crude.

Care for Providers

Because resident care is so intimately related to working conditions, the mix and number of staff per patient, as well as the diaper policy and its application, can be used as indicators for both resident care and care for providers. Here, we briefly review these from the perspective of providers before turning to suggestions for additional indicators related to violence and injury. All four—staffing, incontinence policies, violence and injury—are interrelated but different indicators for each would help draw out important differences and the extent of the inequity. We would include an additional indicator that comes out of the feminist literature on women's work; namely the impact of work on private life. Issues of violence, injury and unpaid work are particularly important for this labour force because the overwhelming majority is female and many are from racialized groups and/or immigrant communities. As Karen Messing has so clearly established in her book *One-Eyed Science*, researchers, policy makers and employers have largely ignored their health issues in care work.

Staffing has an obvious impact on providers. With fewer staff, each of them must work harder and faster.

You're always busy running. Like there isn't enough time... you can get the tasks done but you're running all the time. You feel like you're on a treadmill all the time. You're rushing to try and get the requirements finished. (Armstrong, Armstrong and Daly)

But staffing levels can have an impact that goes beyond the rush. In order to get the assigned tasks completed in the allotted time, the providers have to treat the residents in ways that conflict with their own sense of what is personhood, of

what is respectful care. For example, workers described how they have to feed simultaneously three or four residents in order to get everyone finished in their time slot. "It's horrible when you're shoving it in there" (Armstrong, Armstrong and Daly i). Others in this group interview sat nodding their heads in agreement. Their views echo those expressed by those who wrote in comments on our 2004 survey (Armstrong and Daly 18). They "are simply not able to meet that need, which is a stress on the resident as well as on us." Or as another explained by Armstrong and Daly:

We have not time to talk to residents and do the little things that count. We have no social contact with the residents because we have no time due to lack of staff. I would like to see more time with the residents and just taking time out to socialize with them. They're humans and they need contact just like we do. (19)

The data from our 2007 survey (Armstrong, Armstrong and Daly) indicate that more than a third of respondents felt inadequate all or most of the time because residents were not receiving the care they should. This was the case for over 40 percent of the personal care workers who provide most of the care, and for 39 percent of the RNs; another 48 percent said they felt this way sometimes.

Incontinence policy can have a similar impact, undermining the dignity of the providers as well as that of the residents. In one 2007 interview, workers reported that diapers are expected to last eight hours. There is "a strip on the systems and they want them actually wet tip to tip before we should be changing these." Workers must put "stamps on them when we check them" and they are required to date and sign the diaper. "When you put it on and when you check it, if the brief wasn't utilized to capacity, I have to put a line where the

blue line was and say 'AB 0900' and then put the date." But the workers stopped signing, refusing to carry out work that they saw as invading the bodily integrity of the residents and challenging the workers' self respect. "If they want to date and sign it they can date and sign it." Another added, "If we have to send somebody to the hospital, we change it cause I'm embarrassed to send somebody with my signature on it. It's embarrassing" (Armstrong, Armstrong and Daly).

Staffing levels are related to the very high illness and injury rates in long-term care. Care providers in these facilities experienced higher rates of injury and illness than in any other industrial sector, and research in British Columbia has shown that workload is an important determinant of these injuries (Cohen et al.). The workplaces with the lowest staff level have the highest injury rates. Equally important, variation across provinces and institutions suggest that such illness and injury rates are far from inevitable (Yassi et al.). In our 2003 survey (Armstrong, Jansen, et al.), a stunning 97 percent reported being ill or injured as a result of work in the last five years. Being sick does not necessarily mean staying home. In our 2007 study (Armstrong, Armstrong and Daly), 42 percent said they had gone to work two to five times in the last year even when they were sick or injured, while another 18 percent said they had done so more than five times. The respondents made it clear why they thought the illness and injury rates are so high. "We are on the run off our feet to get our work done. Therefore, we've had an increase of work-related injuries, more off sick with stress."

The stress is felt by the residents. Residents' frustration and lack of care, as well as the new mix of patients and the growing number with severe mental illnesses, all contribute to the increasing level of resident to worker violence. Almost all the workers in the 2003 survey (96 percent) indicated that some type of violent incident had occurred in the last three months. In our 2007 survey, a shocking one

in four said they were subjected to physical violence by a resident or a relative more or less every day, and 30 percent said they worried a great deal about the violence of residents.

The stress, workload and work organization that contribute to high illness and injury rates also have an impact on their lives outside work. As one explained, "The work we do is so very demanding I am sometimes so stressed I don't sleep well worrying about work." Or as another put it, "Because I am both physically and mentally exhausted at the end of my work day, when I get home I do not have any energy left to anything else." This is consistent with what we heard on our 2004 survey (Armstrong and Daly), and with the overall responses to the 2007 survey. In the most recent survey, a quarter of the respondents said that thinking about work almost always or often keeps them awake at night and another quarter said this is sometimes the case.

The impact is felt by others at home and is particularly a problem for women who bear the main responsibility for the unpaid care and household chores. "The work we do is so physical that I'm so tired I am grouchy when I get home," wrote one 2007 survey respondent. She was far from alone in linking staffing, workloads and negative consequences for work and relations at home. Another wrote on her survey that "staffing not being increased to compensate for the extra workload and my family ends up bearing the bunt of it. I do enjoy working with residents and my co-workers but wish I had more time to give the residents while at work" (Armstrong, Armstrong and Daly). One worker wrote that she is "always tired, mentally stressed," which leads her to "take frustration out on husband," while another reported that, "I seem to use up all my patience at work. Sometimes, being a single mother, I find myself short-tempered at home" (Armstrong, Armstrong and Daly).

In short, staffing and diaper policies are indicators of healthy conditions for both residents and providers. Because they influence the nature

of care and the conditions for care workers, they also have an impact on the conditions for equity understood in terms of the bodily integrity and personhood of workers as well as of residents. Violence, illness and injury rates also provide critical indicators for an often neglected aspect of women's paid work. These rates not only indicate equity for the health of workers but also the conditions for

expanding hospital system, while mainly state funded chronic hospitals looked after those with severe physical disabilities and psychiatric hospitals received the bulk of those diagnosed with mental health problems. For the most part, these hospitals were covered by the *Canada Health Act* and did not charge fees.

There were also places called nursing homes that were mainly small,

their care. The elderly in particular were disparagingly described as "bed blockers" who should be in long-term care facilities, where fees could be charged. Arguments about dignity, respect and personhood—arguments that have been used to demand and support the deinstitutionalization of some psychiatric patients in the 1960s—were combined with neo-liberal and neo-conservative ideas of the

Staffing and diaper policies are indicators of healthy conditions for both residents and providers. Because they influence the nature of care and the conditions for care workers, they also have an impact on the conditions for equity understood in terms of the bodily integrity and personhood of workers as well as of residents.

care and the costs to employers and the public in the long run. They are therefore critical components in our suite of indicators for equity.

Ownership of Care Facilities

There is another indicator to add to this suite, an indicator that links conditions inside facilities to larger structures. Ownership and payment patterns establish important contexts for equity in long-term care. Ownership, in turn, reflects and influences state actions at the international, national, and local levels. It is linked to, and has an impact on, ideas about welfare, states, and management. It shapes conditions for democratic participation and access. It thus provides another useful component in the suite of indicators of equity in welfare states.

Ontario provides one example. This province has a long history of state involvement in facility care for those who are elderly and poor. In the years immediately after World War Two, this initially took the form of legislation requiring each municipality over a certain size to establish and maintain a home for the aged. The facilities were intended as homes for those unable to care for themselves. Those who were defined as in need of medical care were sent to the rapidly

often family-owned enterprises that catered to those needing some nursing care but who were ineligible for either homes for the aged or hospitals. There were also charitable homes that provided for similar kinds of residents. After a very public exposure of appalling conditions in some private and charitable homes, the government introduced legislation that provided for standards and monitoring as well as some public subsidy (Struthers). Although fees could still be charged in all three kinds of facilities, the rates for the most basic care meant those eligible for a pension from the Canadian government could cover the fees. There was a way to get more privacy and perhaps more of some kinds of care through additional fees, but at least basic care was accessible to most people.

By the 1990s, new pressures were at work in and outside Canada leading to new patterns in care and ownership (Harrington et al.). Government debt was used as the justification for massive cuts in state services, including in health care. Coinciding with some new medical technologies, these cutbacks resulted in the closure of hospital beds and the deinstitutionalization of much medical care. People were sent home quicker and sicker, or refused entry on the grounds that hospitals were inappropriate for

1990s to justify the closure of chronic care and psychiatric hospitals.

Meanwhile, health care services were becoming big business. Governments in Canada increasingly embraced a business model inside government, including in health care. Internationally, Canada became an active player in efforts to ensure free trade for corporations seeking profits, and agreed that government supports and regulations should be limited, at least with regard to the for-profit sector. In Ontario, the Conservative government of Mike Harris undertook an expansion in long-term beds that would be licensed by the government and heavily subsidized from the public purse. The beds were put out for competitive tender, under conditions that favoured large, for-profit corporations engaged in the business of care. As a result, there was a massive shift in the ownership of long-term care beds. Now the majority are in for-profit homes and most of these belong to major, international corporations.

The research we have that compares for-profit with not-for-profit facilities indicates that the quality of care is lower in for-profit facilities and the costs higher. This is not surprising, given that a systematic review of the literature shows a pattern of lower quality care in for-profit compared

to not-for-profit facilities (McGregor and Roland) while the research in Ontario by Sigma-3 reveals that for-profits spend more of the additional money for care on diapers, compared to the not-for-profit homes. Given the connections established between staffing and bodily integrity, the research we have suggests it would be useful to add ownership to the suite of indicators of equity. Moreover, private ownership often means greater secrecy in government contracts based on the argument that confidentiality is required for competition. As a result, there may well be less accountability to the public, and thus, less democratic participation in what is a publicly-funded service. This, too, could be an indicator of equity.

Conclusions

In this paper, we argue that, based on a suite of indicators, long-term care can serve as an overall indicator of equity in welfare states, and thus, as a way of exploring equity within and across national boundaries. Long-term care allows us to explore states on multiple scales. It involves international actions, as well as national and local ones that shape and are in turn shaped by ideas about, as well as provisions for, equity. Long-term care also reflects state approaches to legislation, regulation and monitoring, along with approaches to the provisions of services for both those who provide care and for those with care needs. Together, these activities set the conditions for democratic participation in decisions about the nature and conditions of care.

An exploration of long-term care allows us to assess the extent to which the four principles of bodily integrity, personhood, access and diversity apply to care for those who are among the most vulnerable, and for those who are least likely to contribute to productive labour. With a workforce that is female-dominated, as well as increasingly populated by racialized groups, and a population that is primarily female but diverse in terms

other social locations, it offers a way of examining equity within and across gender lines.

Using long-term care as a means of assessing equity requires a suite of indicators within the larger one of long-term care. We have suggested several key ones here, based on our research in the field, but others are clearly possible. What we maintain, however, is that these indicators must involve both qualitative and quantitative methods. Our survey research suggests that quantitative measures both limit response and underestimate the extent to which practices differ from formal standards and official data. We also argue that both workers and residents should be involved in the development of methods, and as respondents in the research, because they are the ones who know what happens on a daily basis and because this, too, is a form of democratic participation.

Indicators can, if developed in democratic and appropriate ways, help promote democracy by allowing people a means of assessing equity not only in relation to care but also in relation to the overall values and practices that shape welfare states. Long-term care is an indicator that addresses how states treat those who are among the most vulnerable and thus the extent to which equity is manifested in practices.

Pat Armstrong is a Distinguished Professor in the Department of Sociology and the Department of Women and Gender Studies at York University. She has held a Canada Health Services Research Foundation/Canadian Institutes of Health Research Chair in Health Services and is primary investigator on a SSHRC-funded international research project to identify promising practices for understanding and organizing long-term residential health care. She has authored, co-authored or co-edited over 20 books, including Women's Health: Intersections of Policy, Research and Practice (2008), Critical to Care: The Invisible Women in Health Services (2008). In addition, Armstrong has served as an expert witness in more

than a dozen cases heard before bodies ranging from the federal court to federal human rights tribunals on issues related to women's health-care work and to pay equity.

Hugh Armstrong is a Professor with the School of Social Work and the Institute for Political Economy at Carleton University. Dr. Armstrong's areas of research interest include long-term care, the political economy of health care, unions and public policy, and the organization of work, families and households. He is the author and co-author of many books and articles, including most recently, "Structural Violence in Long-Term Care" in Women's Health and Urban Life (2011).

Tamara Daly is a health services researcher and a political economist who studies health care work, aging and long-term care policy, and gender and health policy. She was recently awarded the 19th annual Labelle Lectureship in health economics and policy research. Dr. Daly's recent work has produced many co-authored publications including They Deserve Better (2009 CCPA), policy reports on health care related issues, and many articles on long-term care work and aging.

¹For further information on rates and other details, see <http://www.gov.on.ca/ltc/27_pr_faq.html#1>.

References

- Anand, Sudhir, Fabienne Peter and Amartya Sen, eds. *Public Health, Ethics and Equity*. Oxford: Oxford University Press, 2004. Print.
- Armstrong, Pat and Tamara Daly. *There Are Not Enough Hands: Conditions In Ontario's Long-Term Care Facilities*. Toronto: CUPE Ontario, 2004. Print.
- Armstrong, Pat and Irene Jansen, with Mavis Jones and Erin Connell. "Assessing the Impact of Restructuring and Work Reorganization in Long-Term Care." *Head, Heart and Hand: Partnerships for Women's Health in Canadian Environments*. Vol. 1. Ed. Penny

- Van Esterik. Toronto: National Network on Environments and Women's Health, 2003. 175-217. Print.
- Armstrong, Pat, Hugh Armstrong, and Krista Scott-Dixon. *Critical to Care: The Invisible Women in Health Services*. Toronto: University of Toronto Press, 2008. Print.
- Armstrong, Pat, Albert Banerjee, Marta Szebehely, Hugh Armstrong, Tamara Daly, and Stirling Lafrance. *They Deserve better: The Long-term Care Experience in Canada and Scandinavia*. Ottawa: Canadian Centre for Policy Alternatives, 2009. Print.
- Blake, Raymond, Penny Bryden and J. Frank Strain, eds. *The Welfare State in Canada: Past, Present and Future*. Concord: Irwin, 1997. Print.
- Castle, Nicholas, Steven Handler, John Engberg, and Kristen Sonon. "Nursing Home Administrators' Opinions of the Resident Safety Culture in Nursing Homes." *Health Care Management Review* 32.1 (2007): 66-76. Print.
- Christie, Nancy. *Engendering the State: Family, Work and Welfare in Canada*. Toronto: University of Toronto Press, 2000. Print.
- Cohen, M, J. Village, A. S. Ostry, P. A. Ratner, Y. Cvitkovich, A. Yassi. "Workload as a Determinant of Staff Injury in Intermediate Care" *International Journal of Occupational and Environmental Health* 10 (2004): 375-383. Print.
- Coroner's Jury. Verdict in the Death of Ezzeldine El Raubi at Casa Verde, Toronto, April 18, 2005.
- Corrêa, Sonia. *Population and Reproductive Rights: Feminist Perspectives from the South*. London: Zed Books, 1994. Print.
- Dobrowolsky, Alexandra, ed. *Women and Public Policy in Canada: Neoliberalism and After?* Toronto: Oxford University Press, 2009. Print.
- Esping-Andersen, Gosta. *The Three Worlds of Welfare Capitalism*. Princeton, NJ: Princeton University Press, 1990. Print.
- Guberman, Nancy. "Designing Home and Community Care For the Future: Who Needs to Care?" *Caring For/Caring About: Women, Home Care and Unpaid Caregiving*. Ed. Grant, Karen et al. Aurora: Garamond, 2004. Print.
- Hampton, Howard. "Archie Campbell." *Legislative Assembly of Ontario*. 25 April 2007. Transcript. Web.
- Harrington, Charlene, Clarilee Hauser, Brian Olney, and Pauline Vaillancourt-Rosenau. "Ownership, Financing and Management Strategies in the Ten Largest For-profit Nursing Home Chains in the United States." *International Journal of Health Services* 41.4 (2011): 725-46.
- Hillmer, M. P., W. P. Wodchis, S. S. Gill, G. M. Anderson, and P. A. Rochon. "Nursing Home Profit Status and Quality of Care: Is There Any Evidence of Association?" *Medical Care Research Review* 62.2 (April 2005): 139-66. Print.
- Huber, Manfred. *The Need to Improve the Comparability of Long-Term Care Expenditure Data: Recent Estimates from a Selection of OECD Countries and Follow-Up Work*. Paris: OECD, 2005. Print.
- Kelly, A., J. Conell-Price, K. Covinsky, I. Stijacic Cenzer, A. Chang, W. J. Boscardin, and A. K. Smith. "Length of Stay for Older Adults Residing in Nursing Homes at the End of Life." *Journal of the American Geriatrics Society* 58 (2010): 1701-1706. Print.
- Lane, C. J., S. E. Bronskill, K. Sykora, I. A. Dhalla, G. M. Anderson, M. M. Mamdani, S. S. Gill, J. H. Gurwitz, and P. A. Rochon. "Potentially Inappropriate Prescribing in Ontario Community-Dwelling Older Adults and Nursing Home Residents." *Journal of the American Geriatric Society* 52.6 (June 2004): 861-6. Print.
- Lewis, Jane and Rebecca Surrender, eds. *Welfare State Change: Towards a Third Way?* Oxford: Oxford University Press, 2004. Print.
- Long Term Care Homes Act*, 2007. S.O. 2007, Ch. 8. Web.
- Martin, Paul. "Address by Prime Minister Paul Martin at the First Ministers' Meeting." Speech. Health Canada, Ottawa, Ontario, 13 Sept. 2004. Web.
- Messing, Karen. *One-Eyed Science Occupational Health and Women Workers*. Philadelphia: Temple University Press, 1998. Print.
- McGill Institute for Health and Social Policy. "The Work, Family and Equity Index (WFEL)." *Raising the Global Floor*. 2 May 2011. Web.
- McGregor, Margaret and Lisa A. Ronald. "Residential Long-Term Care for Canada's Seniors: Nonprofit, For-Profit or Does it Matter?" *Institute for Research on Public Policy Study* 14 (January 2011). Print.
- Organization for Economic Cooperation and Development (OECD). *Help Wanted?: Providing and Paying for Long-Term Care*. Paris: OECD, 2011. Print.
- Petchesky, Rosalind Pollack. *Global Prescriptions: Gendering Health and Human Rights*. London: Zed Books, 2003. Print.
- Rochon, Paula A, Therese A. Stukel, Susan E. Bronskill, Tara Gomes, Kathy Sykora, Walter P. Wodchis, Michael Hillmer, Alexander Kopp, Jerry H. Gurwitz, and Geoffrey M. Anderson. "Variation in Nursing Home Antipsychotic Prescribing Rates." *Archives of Internal Medicine* 167.7 (April 2007): 676-683. Print.
- Rochon, P. A., A. Mashari, A. Cohen, A. Misra, D. Laxer, D. L. Streiner, J. P. Clark, J. M. Dergal, J. Gold. "The Inclusion of Minority Groups in Clinical Trials: Problems of Under Representation and Under reporting of Data." *Accountability in Research* 11.3,4 (July-December, 2004): 215-23. Print.
- Romanow, Roy J. *Building on Values: Final Report of the Commission on the Future of Health Care in Canada*. Ottawa: Public Works and Government Services Canada, 2002. Print.
- Sainsbury, Diane, ed. *Gender and Welfare State Regimes*. Oxford: Oxford University Press, 1999. Print.

- Sigma-3 Policy Research Inc. *Nursing and Personal Care: Funding Increase Survey*. Toronto: Ministry of Health and Long Term Care, 2003. Print.
- Smith, Monique. *A Commitment to Care: A Plan for Long-Term Care in Ontario* Toronto: Ministry of Health and Long-Term Care, 2004. Print.
- Standing, Hilary. "Gender Equity and Health Indicators in the Context of Health Reform." *International Journal of Public Health* 52 (2007): 55-56. Print.
- Statistics Canada. "A Portrait of Seniors." *The Daily* 27 February 2007. Web.
- Struthers, James. "Reluctant Partners: State Regulation of Private Nursing Homes in Ontario, 1941-1972." *The Welfare State in Canada: Past, Present, and Future*. Ed. Raymond B. Blake, Penny E. Bryden, and J. Frank Strain. Concord: Irwin Publishing, 1997. 171-192. Print.
- van Doorslaer, E., C. Masseria, and the OECD Equity Research Group Members. *Income Related Inequality in the Use of Medical Care in 21 OECD Countries*. Paris: OECD, 2004. Web.
- Williams, Fiona. *Claiming and Framing in the Making of Care Policies: the Recognition and the Redistribution of Care*. Geneva: United Nations Research Institute for Social Development, 2009. Print.
- Witmer, Elizabeth. "Long Term Care." *Legislative Assembly of Ontario*. 23 November 2006. Transcript. Web.
- Yassi A., M. Cohen, Y. Cvitkovich, I. H. Park, P. A. Ratner, A. S. Ostry, J. Village, and N. Polla. "Factors Associated with Staff Injuries in Intermediate Care Facilities in British Columbia" *Nursing Research* 53.2 (2004): 87-98. Print.

MARGO SWISS

Women Tell

Women tell of their babies that died:
 ones born black as your boot, grey or blue
 ones that lived just a day or two
 ones that slept with death in their cribs
 ones that were spindly and could never suck
 ones that were taken before they wore clothes.

Women tell of the nurseries they made:
 linens and lamps, assorted notions of joy,
 the patient passing of nine months gone
 as on a long trip, heavy with love for the unexpected
 to be finally rejected by somebody special
 who never arrived, a door slammed in the face,
 the place they came to a vacant space,
 a house abandoned and all swept clean
 with only a simple sign on the door,
no body lives here any more.

Margo Swiss's poetry appears earlier in this volume.

ILONA MARTONFI

Father's Wake

"Tomorrow is the funeral," she said.

She talked and talked, and consoled me with her voice.
 Mother talked about her duties to him: how she had filled
 the vials for his injections. Now she didn't have to do it
 anymore. She prepared his Sunday suit, his shirt, his tie,
 and shoes, to take to the Verhoeve Funeral Home.

"Death roamed the house for weeks," my father had said.

Ilona Martonfi's poetry appears earlier in this volume.