

What Does the Future Hold for the Prevalence and Fiscal Implications of Disability in Canada

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Abstract

While Canadians are typically proud of their universal health care, this publicly-funded care was adopted in the 1960s when the major costs were doctors and hospitals. As a result, long term care was not considered, and at present is only partially covered by public programs, and only in a patchwork manner. There is both great interest, and great concern, therefore, in what the future holds in terms of the prevalence of disability, especially among the elderly, and in turn what the likely program costs would be to extend public programs to offer fuller coverage of long term care. This paper first briefly reviews the various conceptual frameworks for measuring disability, including the 1982 WHO ICIDH and the 2002 WHO ICF. Next, we have examined the prevalence distributions of disability (by age group, sex, and some derived index of severity) for several data sets. Earlier work has indicated that we can expect major inconsistencies. While conceptually there is no "right answer" as to which measures are correct, the practical benchmark is how various kinds and levels of disability translate into programmatic long term care needs. Finally, we have used these detailed data to construct a plausible scenario for the next 30 years projectiing the needs for and costs of long term care for the population age 65+

<u>Introduction</u> Canada, like most countries, is experiencing population aging. And like other countries, there are associated concerns about the fiscal sustainability of publicly-funded health care. In Canada, a current aspect of these concerns is long term care (LTC) for the elderly.

While Canadians are typically proud of their universal health care, this publicly-funded first dollar coverage for care was adopted in the 1960s when the major costs were doctors and hospitals and the focus was on acute care. As a result, LTC was not considered, and at present is only partially covered by public programs, and then only in a patchwork manner. However, with population aging, there is an increasing focus on chronic disease. There is both great interest, and great concern, therefore, in what the future holds in terms of the prevalence of disability, especially among the elderly. In turn there are major questions regarding how the needs for LTC will be met – via public programs, private insurance, or directly out-of-pocket, or not met at all.

In this paper, we address these questions in several steps. We first explore the concept of disability, both generally and as it relates to the needs for LTC. Then, drawing on a number of household surveys, we develop estimates of the prevalence of disability focusing on the elderly population, and the extent of unmet needs for LTC. These data show considerable variation in the prevalence of disability depending only on how it is measured. Finally, we combine these data with a range of other data and use Statistics Canada's LifePaths microsimulation model (Spielauer 2013) to project LTC needs and costs under several scenarios.

<u>Concept of Disability</u> There is a long history of competing concepts of disability. One milestone was the publication of WHO's ICIDH = International Classification of Impairment, Disability and Health (ref). The objective of the ICIDH was to provide, for the first time and in contrast to the century old ICD (International Classification of Disease ref), a rigorous

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methodology and typology for assessing functional health – a more vernacular approach to conceptualizing health rather than one based on biology and clinical approaches.

While the ICIDH represented a major advance, it was seriously criticized by the disability community because it implicitly defined disability as arising solely from impairments of the individual. It was criticized as having a "blame the victim" aspect by the disabled community as it paid no attention to barriers and facilitators to functioning situated in the physical and social environment. As a result, WHO embarked in the early 1990s on a revision that led to the ICF = International Classification of Functioning, Disability and Health (ref). The ICF introduced the ideas of "Activity" and "Participation" with the intent to provide a balance between limitations in functioning arising "within the skin", and those arising because of environmental barriers and facilitators. In theory, the Activity portion of the ICF was intended to deal with the former, while the Participation section would reflect the latter.

The ICF as adopted, however, was at the time and remains seriously flawed in clearly demarcating this distinction. Furthermore, the ICF is a very lengthy list of kinds of activities and forms of participation so that it does not lend itself well to practical use in clinical settings, and certainly not directly to statistical data collection.

In a separate thread, the health economics literature has long been built in the idea of a QALY = quality-adjusted life year (ref Gold et al. etc.). The essence of a QALY is that it provides a single numerical score in the [0,1] interval for the overall health or functional status of an individual, with 1 representing "full health" and 0 indicating death. (Negative QALY values are also possible, representing living states judged to be worse than death.) QALYs are typically based on a set of dimensions or domains of functioning like vision, mobility and pain, and incorporate a formula that maps levels of functioning on each domain in the set into the index. QALYs have been operationalized in several forms, the most widely used systems of measurement are the EQ-5D (a standardized instrument developed by the EuroQol Group with a descriptive system comprising five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression, ref) and the McMaster HUI = health utility index in turn based on a health-status classification system with eight domains (vision, hearing, mobility, dexterity, emotion / depression, speech / communicating, cognition, and pain).² (ref)

Yet another strand of disability measurement, the oldest, is based on an individual's performance of ADLs = activities of daily living (e.g. moving about, bathing, and dressing), and IADLs = instrumental activities of daily living (e.g. shopping for groceries, doing banking). This approach to assessing functioning is useful at a fine-grained level, but generally does not support the construction of QALYs needed for health economics analysis. Further, since ADL and IADL questions vary so much across surveys, even within a country let alone internationally, and there are no clear principled methods for aggregating them, they are not well-suited for summary information on trends or other kinds of comparisons of the prevalence of disability. Often, ADL and IADL questions on household health and disability surveys are accompanied by questions about whether the individual with ADL and IADL limitations received any help, or needed help, with those activities. Thus, the ADL + IADL questions, when combined with the questions about receiving help, enable some of the distinction between "within the skin" functional limitations and those associated with environmental barriers and facilitators to be made.

Another often used set of terms in this context is "capacity" and "performance". Capacity is defined in terms of whether an individual is able to do something on their own, e.g. see or move about. Performance refers to whether or not they actually do the function, in turn depending not only on their intrinsic ("within the skin") capacity but also on the physical

² There are older, widely used generic health status measures like the SF-36, but they are unsuitable for use as the foundation for QALYs because there is no rigorous way to transform the series of questions on level of functioning in each domain into a numerical index (though not for want of trying, ref SF12 etc.).

and social environment. But these are not the best terms or concepts for making a clear distinction between disability arising from "within the skin" impairments and disability arising due to environmental factors, e.g. kneeling bus transportation and social stigma.

Finally, there are definitions of disability implicit in the program eligibility criteria for LTC. These need not overlap with widely used concepts and measures of disability in household surveys. For example, blindness is almost universally considered a disability, yet may count little or not at all toward eligibility for LTC. In contrast, incontinence is generally not even included in household survey measures of disability, yet can be a strong predictor of eligibility for LTC.

For purposes of this analysis, we are constrained by the available data, to which we turn next.

Disability Data For this analysis, we focus on three large household surveys:

- the post-censal PALS = Participation and Activity Limitations Survey in 2006,
- the 2009 CCHS = Canadian Community Health Survey with its focus on healthy aging, and
- the post-censal 2012 CSD = Canadian Survey of Disability.

The CCHS and PALS included both the eight domain HUI question set and ADL/IADL questions, while the CSD based its disability prevalences on a similar but not identical set of functioning domains as the HUI. The individual's degree of difficulty on each functioning domain was weighted by a complicated scoring grid using responses to questions on whether the functional limitations were "limiting" in daily activities, resulting in what the CSD called a "social model" of disability (CSD 2012, ref). In this section, we compare and contrast the resulting estimates of disability prevalences across these three datasets and the different approaches.

Figure 1 presents six different estimates of the prevalence of disability among the household population of Canada from the three surveys. The general patterns of increasing prevalence with age, and higher disability rates for women than for men are consistent for all estimates. However, the levels of disability can differ widely.

Figure 1 – Six Estimates of Disability Prevalence by Age Group, Sex, and Severity









c. PALS HUI Four Domains (from "PALS 2006 ... mcw g")

e.

d. CCHS HUI for Four Dimensions (from dismatrix HUI4 mcw e)

PALS ADL-based (from "PALS 2006 ... mcw g") f. CCHS HUI Index by Range (from HUIDHSI CCHS 2009 mcw c) (BJM: Good to indicate in the graph that proportion with at least one activity limitation)



For Figures 1a to 1d, the top curve is those without disability, and the lower three curves are incremental, starting with "mild" disability, then "mild" + moderate", and finally "mild" + "moderate" + "severe" (and in Figure 1.b also + "very severe") disability. Figure 1.e is based on a single 2006 PALS derived variable based on whether the individual had at least one activity limitation. Finally, Figure 1.f is based directly on the HUI index values observed. This index is based on

5

a formula for individual preferences among health states estimated empirically (HUI ref). In this latter case, the curves represent the percentages of the population at each age with HUI index or utility values below the (arbitrarily chosen) thresholds indicated: .25, .5, .75. and .95.

Ostensibly, Figures 1.a and 1.b should be quite close since they are based on very similar definitions of ADL limitations. Figures 1.c and 1.d should be even closer since they are using the same definitions derived from identical HUI domain questions. However, in both pairs there are wide differences. (n.b. the age ranges along the horizontal axis are different. The 2009 CCHS only sampled individuals age 45 and higher; and the downloaded CSD data did not provide the same age groups.)

For both pairs, the prevalence of disability increases with age, and females have higher prevalences than males. However, the sex difference is much larger for the 2009 CCHS data than in the 2012 CSD. And the reported severity of disability is much higher in the CSD than in the CCHS, i.e. the prevalence of mild and moderate disability is much higher in the CCHS. The 2006 PALS, shown in Figure 1.c, indicates an even higher prevalence of disability based on reported ADL limitations.

To some extent, these differences may reflect the algorithms used to derive the overall disability categories from the underlying questions in the three surveys (except 1.c and 1.d which are, by construction, the same). But they may also reflect differences in the framing of the surveys, e.g. individuals are more likely to report a disability and to rate its severity higher in a "disability" survey than in a "health" survey. Finally, there were important differences in the ways the survey samples were drawn³ and data collected, including the screening questions, skip patterns, sample design, direct or proxy respondents, and face-to-face vs phone interviews.

Figures 1.d and 1.f are both based on the same HUI set of questions and the same 2009 CCHS as also used in Figures 1.a. Figure 1.f uses the published HUI index (HUI ref) and shows the distribution of HUI index scores by age group and sex. However, the HUI index is not likely to correspond to the kinds of functional limitations that mirror most closely the factors used to determine needs and eligibility for LTC. We have therefore constructed another index based on four of the eight HUI domains judged to be most relevant to determining LTC needs: mobility, cognition, dexterity, and pain. As a result, limitations in the other four HUI domains – vision, hearing, emotion / depression, and speech / communication – are not considered. It is this four-domain variable derived from the HUI questions (HUI4) that is graphed in Figures 1.c and 1.d. Comparing Figures 1.d and 1.f, and considering the series of HUI index value thresholds in Figure 1.f to correspond approximately to severe <.25, moderate between .25 and, .75, and mild or no disability to be >.75, then these two graphs show quite similar patterns, though again significant differences in levels.

³ The2006 PALS survey was drawn from those responding affirmatively to a small set of disability screening questions on the 2006 population census, while the 2009 CCHS and 2012 CSD were based on clustered and stratified geographic area samples.



Figure 2 – PALS 2006, Self Reported Health Among Those Reporting "At Least One ADL" by Sex and Age Group

Figure 2 shows the distributions across levels from the very widely used "self-reported health" question for those who responded with at least one ADL limitation on the 2006 PALS as shown in Figure 1.e. In all sex and age groups in Figure 2, at least 50% of those with an ADL reported their health as good, very good or excellent. One possible explanation for such large proportions of ostensibly disabled individuals reporting such goo health is that having at least one ADL is not that serious a problem for a great many individuals; so simply counting up affirmative responses to having one or another ADL is a very poor indicator of non-trivial disability, i.e. disability where LTC services are needed. This possibility is consistent with the substantially lower levels of disability from the 2012 CSD shown in Figure 1.b, where in order to be counted as disabled, there had to be not only a functional limitation, but also one that limited daily activities.

Another possibility is that responses to the widely used self-rated health question are heavily influenced by "accommodation", that individuals with ADLs not unreasonably accommodate to their limitations by shifting their expectations as to what good health really means. They adapt, learn to cope, and reduce any cognitive dissonance associated with their ADLs with the result that they rate their health better than they would have done prior to becoming limited.

The 2009 CCHS, since it contained all three of the different ways of assessing disability shown in Figure 1, also enables a comparison of their pairwise joint distributions. These are shown in Table 1. There are clearly correlations, though they are far from tight. These correlations support, as discussed above in the comparison of Figures 1.d and 1.f, considering HUI index values >.75 as either mild disability or no disability, index values in the .25 to .75 range as moderate disability, and index values < .25 as indicating severe disability. We use this approximation subsequently.

	Males Age 65 to 79					Females Age 65 to 79					
	HUI4-	HUI4-	HUI4-	HUI4-			HUI4-	HUI4-	HUI4-	HUI4-	
HUI Index	none	mild	moderate	severe	All HUI4	HUI Index	none	mild	moderate	severe	All HUI4
< .25	0.0	0.2	1.8	0.8	2.8	< .25	0.1	0.1	2.1	1.8	4.1
.26 to .50	0.4	1.5	3.3	0.2	5.5	.26 to .50	0.2	1.8	4.1	0.8	6.8
.51 to .75	1.6	9.8	1.8	0.1	13.4	.51 to .75	1.1	9.8	2.1	0.2	13.2
.76 to .95	16.3	19.2	0.5	0.0	35.9	.76 to .95	13.8	20.3	0.9	0.0	35.0
.96 to 1.0	42.4	0.0	0.0	0.0	42.4	.96 to 1.0	40.9	0.0	0.0	0.0	40.9
All HUI Index	60.8	30.8	7.3	1.2	100.0	All HUI Index	56.1	31.9	9.1	2.8	100.0
	HUI4-	HUI4-	HUI4-	HUI4-			HUI4-	HUI4-	HUI4-	HUI4-	
	none	mild	moderate	severe	All HUI4		none	mild	moderate	severe	All HUI4
ADL-none	58.0	26.9	4.4	0.2	89.5	ADL-none	51.8	25.3	3.9	0.2	81.2
ADL-mild	2.4	3.2	1.9	0.3	7.8	ADL-mild	4.1	6.0	3.9	0.6	14.5
ADL-moderate	0.3	0.6	0.7	0.3	2.0	ADL-moderate	0.2	0.6	1.0	1.0	2.8
ADL-severe	0.1	0.0	0.3	0.3	0.7	ADL-severe	0.0	0.1	0.3	1.1	1.5
All ADL	60.8	30.8	7.3	1.2	100.0	All ADL	56.1	31.9	9.1	2.8	100.0
			ADL-	ADL-					ADL-	ADL-	
HUI Index	ADL-none	ADL-mild	moderate	severe	All ADL	HUI Index	ADL-none	ADL-mild	moderate	severe	All ADL
< .25	1.1	0.9	0.5	0.4	2.8	< .25	0.6	1.4	1.0	1.1	4.1
.26 to .50	3.6	1.2	0.5	0.2	5.5	.26 to .50	3.3	2.5	0.8	0.3	6.8
.51 to .75	10.7	2.1	0.5	0.1	13.4	.51 to .75	8.7	3.7	0.7	0.1	13.2
.76 to .95	32.9	2.5	0.4	0.0	35.9	.76 to .95	30.1	4.7	0.1	0.0	35.0
.96 to 1.0	41.2	1.1	0.1	0.0	42.4	.96 to 1.0	38.5	2.2	0.1	0.0	40.9
All HUI Index	89.5	7.8	2.0	0.7	100.0	All HUI Index	81.2	14.5	2.8	1.5	100.0

Table 1 – Joint distributions of HUI Categorie	-s (HUI4)	HUI Index Intervals, a	nd ADIs ((from nairwise mcw d xlsx)
Table 1 Joint alstributions of fior categorie		, nor mack milling, a		(ITOTTI pati wiseThew u.visv)

<u>Unmet Need Data</u> The next critical question is the extent to which the care needs of the disabled are being met. For this, we have used the 2006 Participation and Activity Limitations Survey (PALS). In addition to the ADL and HUI questions, the 2006 PALS included many questions on needs for assistance and the extent to which these needs were being met.

Figure 3 displays, by sex and age group, the two by two set of possibilities for whether the individual *needs* assistance (no = N0, yes = N1), and whether the individual *receives* assistance (no = R0, yes = R1). The graphs to the left indicate proportions, while those on the right show population counts.

In terms of proportions, those not needing (or receiving) any assistance (N0 R0, bottom bar) decline with age, females more so than males. The proportions needing but not receiving assistance (N1 R0, second bar from top) is generally quite small. A substantial proportion, increasing steadily with age, are receiving care and have their care needs fully met; they do not need further care (N0 R1, second bar from bottom). Still, an increasing proportion do need care even though they are already receiving care (N1 R1, top bar). This latter group is most significant from the perspective of unmet needs for LTC. As a general impression, the proportion of those needing care who are already receiving care, at higher ages, is on the order of at least 50% of those receiving care but not needing further assistance.

Figure 3 – PALS – unmet needs (from "PALS 2006 ... mcw g")





Female Populations that Need or Receive Assistance



Male Populations that Need or Receive Assistance



While the proportions needing and/or receiving care (i.e. NO R1, N1 R0, N1 R1) in the left-hand graphs become larger with age, the absolute numbers of individuals shown in the right-hand graphs are fairly stable across age groups – while the proportions with unmet needs are increasing with age, the total population sizes are decreasing with age.

<u>Disability, Nursing Homes and Retirement Residences</u> – In order to form a view on the likely future needs for LTC, it is essential to bring together data from a variety of sources. The survey data shown above include in their samples only the "household" population. This excludes both those living in nursing homes (NH), and in private "retirement residences" (RRs). In Canada, these RRs are considered "collective dwellings" in the population census, and not part of the household population. These RRs generally offer a common dining room and varying amounts of disability assistance, much but not all of which is paid privately.

Figure 4 shows the distribution of the population by age group, sex, and where they live using 2011 population census data. Figure 4.a on the left shows all age groups while Figure 4.b on the right focuses on those age 65+. It also adds two curves showing the male and female household populations, i.e. the total population minus those of each sex living in nursing homes (NHs) or retirement residences (RRs). Figure 4.a shows that the population living in NHs and RRs is negligible below age 65, so they will be ignored in the analyses below. Figure 4.b which expands the view to focus on the 65+ population highlights the much larger proportions living in collective dwellings, especially in the 80-84 and 85+ age groups. (n.b. the increase in the female population from the 80-84 age group to the 85+ age group reflects the larger range of ages in the latter open-ended interval.) Figure 4.b also adds two curves showing the male and female household populations, i.e. the totals minus those of each sex living in nursing homes (NHs) or retirement residences (RRs). Although the household population continues to dominate, there is a clear decline as the aggregate collective dwelling population rises. It also highlights the very substantial number of individuals living in RRs. The 2011 census was the first in Canada to delineate carefully this sub-population.





Given the importance of collective dwellings in these older age groups, it is critical to find data on disability prevalences for these populations. Even though there are no household survey data, there are administrative data for some provinces, including especially good coverage in Ontario (Canada's largest province with about 40% of the population).⁴ These data are derived from at least annual assessments of functioning for all individuals living in NHs, and all those in RRs who are receiving home care, using a standardized instrument, the Inter-RAI (ref). Further, a mapping has been developed between these routine and very detailed functional limitations assessments and the eight dimensions of the McMaster Health Utility Index (HUI) via a carefully developed algorithm. (ref Bernier, Sanmartin, Hirdes, Health Reports)

Based on this crosswalk between the detailed Inter-RAI data and the HUI, Figure 5 shows the distributions of HUI index values for both sexes, and both HC recipients and NH residents. Note that HC in this case includes home care services provided in private "retirement residences" (RRs) as well as in the usual notion of "home". The HUI distributions show, not surprisingly, significantly poorer health in the NH compared to HC populations. There is some upward trend in severity with age in all four sex-by-setting graphs, though less so for NH than HC. The patterns look similar for men and women. These observations are consistent with eligibility for either HC or NH being relatively unaffected by age and sex.

Based on these and related data, we have constructed overall estimates of the prevalence of disability in Canada, using as close to consistent definitions as possible, spanning households, RRs, and NHs.

⁴ These data include HC data from AB, BC, MB, NS, ON, and YT for 2010 to 2012, and NH data from BC, MB, NL, NS, ON, SK, and YT for 2005 to 20012.



Figure 5 – Imputed HUI Levels by Age Group, Sex, and Persons Living in NHs or Receiving HC







Projecting the Disabled Population – The major public policy concern regarding the likely needs for LTC in coming decades is driven mainly by population projections showing a substantial increase in the elderly population, both in overall numbers and relative to the size of the non-elderly population. It is generally assumed that this increase in numbers of elderly individuals will be accompanied by a corresponding increase in the numbers needing various forms of LTC. However, the numbers needing LTC in future will not depend only on the size of the elderly population. It will also depend on the proportions who are disabled to varying degrees, the kinds of LTC needs they will have, the extent to which these needs can be met from various sources including informal care from relatives and friends, and the kinds of programs and services offered as LTC. Further, these various factors will interact. As a result, there are many uncertainties in any serious projections.

To start, it is important to appreciate the magnitude of the generally accepted projection of mortality improvements. Figure 6 shows the population pyramid for Canada projected to 2050 with (including the red bars) and without (blue bars only) assuming any of the mortality improvements in Statistics Canada's middle projection (ref). There is a very substantial impact on the numbers of individuals especially in the 85+ age group.

Figure 7 shows the historical trends in life expectancy at several ages over more than three decades (ref CANSIM life tables). These historical increases have been quite steady, suggesting that it is reasonable for projections to assume a continuation of these trends.





These mortality projections, when combined with trends in fertility and immigration / emigration rates, form the basis for overall population projections. Figure 8 shows projection results for the next 50 years using the LifePaths model which, in turn assumes the middle Statistics Canada demographic projections. The "ripples" reflect the post-war baby boom, then the "baby bust" decline in fertility rates in the 1960s, followed by the "echo" birth cohort born about 30 years later to the baby boom birth cohort. (ref Foot, "Boom, Bust and Echo")

Figure 8 – Projected Population



Projected Population (millions) by Age Group and Sex

These population projections have been combined with estimates of the future evolution of disability. While there is every reason to expect that the longstanding trend toward increasing life expectancy just shown will continue, there is major uncertainty about the historical trend of disability in Canada, let alone its likely future trend. The debate in the academic literature typically makes reference to James Fries' (ref) notions of expansion or compression of morbidity –

12

<u>Figure 7 -- Trends</u>

whether added years of life expectancy will be mostly years of good health, or years of morbidity (ill health) and disability (i.e. functional limitations, which need not be well correlated with morbidity or ill health in the clinical or biological sense). As an initial assumption, in the analysis presented below we consider only one of these two scenarios, constant age-specific disability patterns, which in the event of increasing life expectancies means expansion of morbidity / disability. To this end, we build on the LifePaths module that simulates and projects disability defined in four levels: none, mild, moderate, and severe. These transition dynamics were estimated from the longitudinal National Population Health Survey (ref NPHS; Wolfson and Rowe, 2008; etc.)

Disability and the Utilization of Home Care and Nursing Home Services – The various distributions of disability shown in Figure 1 pertain only to the household population. To produce estimates for the entire population, we have combined household disability prevalence estimates with the census data in Figure 4. For those in "assisted living" retirement residences (RRs), we have drawn on the administrative Inter-RAI data for home care utilization in Ontario.⁵ These data have been used to classify home care recipients by the level of severity of their disability, as shown in Table 2.

		none	mild	moderate	severe
65-69	Female	6	16	29	50
70-74	Female	4	18	26	52
75-79	Female	3	13	27	57
80-84	Female	2	13	25	60
85+	Female	1	10	20	69
65-69	Male	6	13	31	50
70-74	Male	5	12	27	56
75-79	Male	6	11	28	54
80-84	Male	2	11	26	61
85+	Male	2	9	23	66

Table 2 – Estimated Population Distribution of Disability Rates by Age Group, Sex, and Level of Disability of Home Care Recipients for those living in Retirement Residences in Ontario, 2013 (%)

(from Michael_PSW s.xlsx at AG6)

As is evident in Table 2, a significant proportion of home care recipients have only "mild" and even no disability. Thus, a key set of assumptions is the probabilities, at each of the three levels of disability produced by the LifePaths simulations, of needing either home care (HC) or living in a nursing home (NH). For home care services, we have used the distribution shown in Table 2; for nursing homes, we have simply assumed that all nursing home residents are "severely" disabled, roughly in line with the results shown in Figure 5 above. We have also ignored the very small proportion of the population living in nursing homes under age 65. The result of combining these data for the overall Canadian population is shown in Table 3.

⁵ Kindly provided by John Hirdes and his colleagues.

		none	mild	moderate	severe
65-69	Female	61.2	30.9	5.8	2.1
70-74	Female	54.6	31.3	9.5	4.6
75-79	Female	47.9	30.9	13.1	8.1
80-84	Female	40.8	27.7	18.2	13.3
85+	Female	29.2	17.5	21.1	32.2
65-69	Male	66.3	25.8	6.5	1.4
70-74	Male	56.7	33.5	7.1	2.7
75-79	Male	54.0	33.0	8.8	4.1
80-84	Male	45.6	28.8	17.8	7.8
85+	Male	32.2	25.7	20.3	21.8

Table 3 – Estimated Overall Population Distribution of Disability by Age Group, Sex, and Severity, 2011 (%)

(from Michael_PSW s.xlsx at BA5)

In the LifePaths microsimulation model, disability transition dynamics are represented by multivariate conditional probabilities of moving from one disability state to another, including both declines and improvements. Mortality rates are also conditional not only on age, sex, and calendar year (since these rates are projected), but also on disability level (i.e. none, mild, moderate, or severe). These transition probabilities have been calibrated to reproduce fairly well the prevalence distribution shown in Table 3 for 2010.

The data in Tables 2 and 3, in combination with the disability dynamics estimated from the NPHS and embodied in LifePaths, provide the basis for projections of disability by level of severity (none, mild, moderate, and severe). The results are shown in Figure 9, with the darker colours indicating more severe disability. Especially for females age 85+, the projection indicates a very substantial increase in the severely disabled population.







(from BJM31March2018_2m...p.xlsx in sheet B2_DisCounts)

These disability projections do not indicate directly needs for LTC, though they do provide the basis, conditional on age group, sex, and disability level, for projecting the populations living in RRs and NHs, as well as their utilization of HC.⁶ Thus, in addition to assigning to each individual in a LifePaths simulation a level of disability at each point in time over their life course (n.b. LifePaths simulations occur in continuous time), we also need to assign a residence – either their own home (the "household" population in Stat Can's terms = owner-occupied house or condominium or rented house or apartment), a private-pay assisted living retirement residence (RR), or a nursing home (NH).

We assume that only individuals with some disability choose to live in an RR.⁷ We further assume that once someone has moved from the household population to an RR, they never move back (although s/he can move to a nursing home once severely disabled), and that no one under age 65 lives in an RR.

Similarly, we assume that once an individual has entered a nursing home, they never return to the household or RR population, and that no one under age 65 lives in a nursing home. Further, we are assuming that the only members of the household or RR population that enter nursing homes are already severely disabled.

Since we have no longitudinal data on these transitions, we have used a synthetic cohort approach to estimate the net proportional flows from household to RR or NH, and from RR to NH for recent years, and assumed these transition rates remain constant.

In order to project LTC costs, finally, we need estimates of the consumption of these two main kinds of LTC services, home care and nursing home, in physical units – hours per year and bed-days per year respectively, and then their unit costs. NH consumption is based simply on the fraction of a year an individual is living in a nursing home. However, home care is more complex because even within an age/sex/disability level category, there is a distribution of home care hours consumed.

We have derived estimates of these more fine-grained distributions from the same Inter-RAI data as used above, but specifically only for Ontario. For simplicity, we have represented each of these age group / sex / disability severity / residence groupings' distributions in terms of their means, and the values at each of the 25th and 75th percentiles. In all cases, the 25th percentiles of home care (HC) utilization were at or close to zero. So for each individual we randomly assigned a weekly hours utilization, conditional on age group / sex / disability severity / residence as follows: a 25% chance of zero, a 50% chance of the mean, and a 25% chance of the 75th percentile value. Table 4 shows the resulting estimates.

⁶ Note that about 15% of the patients in hospitals are classified as ALC = Alternative Level of Care. These patients' care should also be considered a form of LTC. However, compared to the NH population, these numbers are very small, so they have been ignored.
⁷ For couples, though, one spouse may not be disabled. We ignore this possibility.

		mean for 25	th to 75th pe	rcentiles of H	IC utilization	75th percentile of HC utilization for top quartile			
		retirement		retirement		retirement		retirement	
	disability	residences	households	residences	households	residences	households	residences	households
age group	level	females	females	males	males	females	females	males	males
65-70	severe	5.1	4.9	4.9	5.8	6.8	6.7	6.4	8.2
	moderate	2.3	2.9	2.3	3.2	3.3	3.1	3.3	4.1
	mild	2.0	2.1	2.1	1.8	2.4	2.4	1.8	2.2
70-75	severe	5.9	5.5	6.1	6.1	5.2	7.0	7.0	8.8
	moderate	3.9	2.9	4.6	2.8	4.5	3.1	4.0	3.4
	mild	1.7	1.9	2.2	1.6	2.8	2.3	2.9	2.0
75-80	severe	6.7	5.8	9.0	6.7	6.8	7.0	6.7	9.0
	moderate	2.8	2.8	3.5	2.9	3.8	3.1	3.8	3.3
	mild	2.3	1.8	5.7	1.8	3.5	2.1	1.8	2.0
80-85	severe	7.2	6.2	6.5	6.3	7.0	7.1	6.6	8.4
	moderate	3.9	3.0	3.9	3.3	3.6	3.3	3.9	3.7
	mild	1.9	2.0	2.3	1.8	3.0	2.1	3.2	2.0
85+	severe	8.1	6.9	7.8	7.1	6.9	8.6	6.9	8.9
	moderate	3.6	3.2	2.9	3.3	4.4	3.9	4.2	3.9
	mild	2.0	2.2	1.4	1.8	3.0	2.5	2.2	2.0

Table 4 – Home Care Services Utilization Distributions by Age Group, Sex, Disability Level and Residence (Weekly Hours)

(from Michael PSW s.xlsx at BR2, sheet MCW on HomeCare)

Finally, we have assigned unit costs to LTC services at the rates of \$300 per bed-day for nursing homes and \$30 per hour for home care, in 2015 dollars. The data in Canada and the provinces on actual unit costs are very poor. Nevertheless, informal discussions with knowledgeable informants suggest these are reasonable estimates.

Projections of LTC Costs and Related Aggregates – We can now turn to the resulting LifePaths projections of key aggregates. Figures 10.a and 10.b show aggregate costs for HC and NH as well as for the Old Age Security (OAS) pension. OAS is a demogrant, i.e. a fixed dollar transfer based only on residence and being age 65+. It is inflation indexed, so constant in real dollar terms. In 2018, it was \$600 per month, equal to about 12% of the average wage. Thus, virtually the entire reason for any changes over time in aggregate OAS expenditures will be the result of changes in the size of the 65+ population. It therefore serves as a useful comparator for the two components of LTC costs, HC and NH.

Figure 10.a on the left breaks out the aggregate costs by sex while Figure 10.b on the right disaggregates by broad age group. It is clear from these charts that LTC costs, especially NHs, are projected to increase much more rapidly in constant dollars than OAS, especially for women (Figure 10.a) and for those age 85+ (Figure 10.b).



(from BJM31March2018_2m...p.xlsx in sheet A2_Counts)

In addition to the OAS budgetary costs, two other comparators are total federal income tax, shown in Figure 11.a, and aggregate wages, shown in Figure 11.b. The comparison with income taxes is formidable, with LTC costs rising from about one-third of income taxes to more than half. it is important to note that most LTC costs are borne by provincial governments in Canada. The projected federal income tax series is shown mainly because it indicates quite a different time trend than the OAS. While the OAS reflects essentially only demographic changes, income taxes primarily reflect real income growth.



Figure 11.a

(from BJM31March2018_2m...p.xlsx in sheet A2_Counts)

While the comparison with income tax revenues in Figure 11.a is daunting, the comparison of aggregate LTC costs with the projection of aggregate wages in Figure 11.b may be considered less so. There is a substantial relative increase, but the costs in no way are "unaffordable".

Still, as noted earlier, there are major uncertainties in these projections. One is the question of expansion or contraction of morbidity, or more correctly in this context, expansion or contraction of periods of disability when lifetimes are lengthening. The projections above have assumed constant disability rates within age groups, hence a form of expansion of disability as a proportion of individuals' increasing life expectancies. This may be a rather pessimistic assumption.

On the other hand, there are at least two other major factors which would act in the opposite direction, to result in even larger projected cost increases for LTC. One is the rates of pay of workers in the LTC sector. There is a general sense that these workers are relatively underpaid. Turnover is high in these jobs, and recruiting LTC workers is often difficult. These factors suggest that wages in LTC are likely to rise over coming decades at a faster rate than the rest of the economy. The other major factor is the extent of currently unmet needs. As shown in Figure 3, if publicly funded programs met all home care needs, the volume of HC could increase by about 50%.

Overall, these aggregate results suggest a potential major challenge for Canada, a significant increase in the costs of publically funded nursing homes. These costs are driven by the size of the population of severely disabled Canadian seniors, the proportion of those severely disabled who transition into nursing homes, and the cost of these facilities (to the public as well as to the individual).

<u>Concluding Comments</u> – This analysis has focused on a major gap in Canada's otherwise universal publicly provided health care, namely long term care (LTC). The objective has been to develop reasonable and sophisticated projections of LTC costs in relation to other major government programs and the broader economy. To do so, we have had to weave together a variety of data.

The starting point is the prevalence of disability by severity. Unfortunately, by comparison of data from several different surveys, and using different ways of eliciting information on disability from respondents in these surveys, we find that there is a substantial amount of variation. These important differences are not the result of conventional sampling error. Rather, they are the likely result of different ways of defining disability, as well as differences in the ways the surveys were undertaken. The incoherence in these disability estimates points to a major source of uncertainty in our projections, and to a serious issue for the statistical system – the need to develop consistent and standardized measures, preferably in line with international development, and in ways that can provide long time series as well as connect to the kinds of disability assessments in growing use administratively within the LTC sector.

Another starting point is understanding the size of Canada's population and its age structure. While demographic projections have been produced by Statistics Canada for many decades, until recently they failed to cohere with the statistics on disability. The main reason is that data from disability surveys are almost always confined to the household population, which excludes those living in what the census calls "collective dwellings", mostly nursing homes and retirement residences. These locations house a very large proportion of the disabled population, so the survey data are very seriously incomplete. In order to surmount this major lacuna, we were able to draw on emerging administrative data from the LTC sector. But this was possible only because of the existence of a previously developed "crosswalk" between the two kinds of disability data.

Given basic demographic projections, we used Statistics Canada's LifePaths model then to project disability, residence location (household, retirement residence, or nursing home) and then project LTC utilization conditionally on these covariates. The disability projections embodied in LifePaths are based on detailed regression analysis of the longitudinal National Population Health Survey (sadly now terminated). However, a critical outstanding question is whether trends in the age pattern of disability, as life expectancy increases, are leading to a greater or smaller proportion of individuals' lives spent living with disabilities of various severities. For want of any empirical basis, we have assumed that age-specific disability distributions will remain constant over coming decades.

The simulation results show quite substantial increases in LTC costs over the years to 2050 in Canada. These results could be unduly pessimistic if increasing life expectancy were accompanied by reductions in age-specific disability rates rather than the constancy that has been assumed. On the other hand, they could well be low if (a) the substantial volume of unmet care needs were to be met by expanding publicly funded LTC, and/or (b) the wages of the low paid Personal Support Workers (PSWs) making up the bulk of the LTC work force were to increase more rapidly than average wages in the economy overall, rather than the assumption actually used that their wages will increase at the same rate.

While this study has focused only on the aggregate costs of LTC, there will continue to be major differences in the experiences of individuals. As shown in Figure 9 above, most Canadians age 65+ in 2050 will likely not be severely or moderately disabled even into their 80s. As a result, their LTC costs, whether paid for publicly or privately, will be small. On the other hand, there will be a substantial minority who will have very large LTC costs, of a size that would bankrupt them if they had to be borne privately. This kind of distribution of individual level disability risks suggests that some sort of expanded public financing or new social insurance will be necessary; private insurance markets for LTC have largely failed for these reasons.

As a result, it will be important to consider alternative policy options for anticipating and dealing with these increasing LTC costs. The LifePaths microsimulation model has been designed for these kinds of analyses, which are planned. At the same time, this analysis provides important evidence regarding the serious gaps in relevant statistics.

While our projected increases in LTC aggregate costs, given their uncertainties, are very substantial, they will emerge gradually over coming decades. They do not peak when the baby boom birth cohort reaches age 65, but rather 20 to 30 years later as this cohort moves into its mid 80s. There is time, therefore, for thoughtful and in depth policy analysis and development. But it is past time for such analysis, and the data on which it should be based, to have been developed. This analysis will hopefully provide both an indication of the prospects, and a clarion call for the needed actions.

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