Long Term Care Covid-19 Commission Mtg.

Shirlee Sharkey SE Health
on Monday, December 21, 2020

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MEETING OF THE LONG-TERM CARE COVID-19 COMMISSION

--- Held via Zoom, with all participants attending remotely, on the 21st day of December, 2020, 11:00 a.m. to 12:00 p.m.

BEFORE:

The Honourable Frank N. Marrocco, Lead Commissioner
Angela Coke, Commissioner
Dr. Jack Kitts, Commissioner

PRESENTERS:
Shirlee Sharkey, President & CEO SE Health
Justine Giosa, Manager, Research Operations SE Research Centre, SE Health
Madonna Gallo, Head of Public Affairs SE Health

PARTICIPANTS:

Alison Drummond, Assistant Deputy Minister
Long-Term Care Commission Secretariat

Ida Bianchi, Counsel Long-Term Care Commission Secretariat

Kate McGrann, Counsel Long-Term Care Commission Secretariat

John, Callaghan, Counsel Long-Term Care Commission Secretariat

Lynn Mahoney, Counsel Long-Term Care Commission Secretariat

Derek Lett, Policy Director Long-Term Care Commission Secretariat

Dawn Palin Rokosh, Director, Operations Long-Term Care Commission Secretariat

Jessica Franklin, Policy Lead Long-Term Care Commission Secretariat

Adriana Diaz Choconta, Senior Policy Analyst Long-Term Care Commission Secretariat

ALSO PRESENT:

Janet Belma, Stenographer/Transcriptionist

I N D E X

The following list of undertakings, advisements and refusals is meant as a guide only for the assistance of counsel and no other purpose

INDEX OF UNDERTAKINGS

The questions/requests undertaken are noted by U/T and appear on the following pages: 53

INDEX OF ADVISEMENTS

The questions/requests taken under advisement are noted by U/A and appear on the following pages: None

INDEX OF REFUSALS

The questions/requests refused are noted by R/F and appear on the following pages: None

-- Upon commencing at 11:00 a.m.

COMMISSIONER FRANK MARROCCO (CHAIR): I'm Frank Marrocco. This is Commissioner Angela Coke; and Dr. Jack Kitts, Ms. Sharkey, you obviously know. We're essentially ready to go. We have a court reporter here. We will publish a transcript of what we've talked about so that people can follow along. We'll ask questions as we go along, if we might, and we're ready to go.

SHIRLEE SHARKEY: Great. Wonderful. Thanks so much. And I really appreciate the opportunity to meet with everyone. I'll be talking about my presentation drawing on, well, quite frankly, my experience in the healthcare system as early on, believe it or not, actually a nurse and a nurse working in the community, a visiting nurse and then a health executive in the acute care, and then also in the community and home care area, but probably most importantly, too, as a family caregiver, I can bring, hopefully, that perspective.

Additionally, in 2008, I had the privilege to work and participate on a report, a 2008 staffing report for long-term care that I'll talk a little bit about, and then lastly, my role

as CEO of Saint Elizabeth Health Care, SE Health, which I've been there for well now over 28 years, and probably the best way to describe SE Health as a non-profit social enterprise is that well now for over 110 years, our key interest has been to really impact how people live and age at home. That's really been the overall focus.

I have with me today, Dr. Justine Giosa, a research scientist at SE Health and co -- principal investigator of our Long-Term Care At Home Study, and that's in partnership with the University of Waterloo and interRAI Canada, and I think Justine will help us work through some of the opportunities and the findings that we have for people both in long-term care homes and in the community.

And also Madonna Gallo is with us, and she is the Head of our Public Affairs at SE Health.

So to start, in February 2020, and I guess you could put up just for your own enjoyment, I actually wrote an article that compared the ongoing transformation of our healthcare system to the movie the Groundhog Day. I hope you've all seen it, and this is with Bill Murray, and he plays a TV weatherman who is, in fact, stuck in a time

loop, and among other things, he keeps stepping off the sidewalk in the same icy puddle over and over again.

And I wrote the article largely about the lack of focus and investment in home care, but I certainly could have written it about long-term care because the same things that I'm sure you have heard, the repetitive cycle in underfunding, how there have been many studies and many reports, all very similar themes.

And I think to date, although there's been some very good work done, I would say that we have not reorientated the system for an aging population, and this, as we know, has been very apparent during the pandemic.

But before we get into the pandemic, I just thought I'd present a context that I think can help describe what's been going on with seniors well before the pandemic. And looking at the latest statistics with C.D. Howe, and that was June 2020, generally, Canada has underinvested in services for seniors; 90% of what is spent on senior care goes, in fact, primarily to institutions, hospitals, and long-term care facilities, and only 10% actually goes into the

community.

Compared to other OECD countries, they spend about 35% in the home and community care side. So we have two problems: The pie that exists for senior care services is certainly or would appear that we are under-investing as a country, and the proportion that goes into the home and community care piece, the 10%, what that really does is eliminates many options for seniors to be able to live in their home longer. It also eliminates options of where they go, and that's why we have the acute care and the long-term care, to some extent, manifesting itself with its challenges.

Then additionally, from research insights, you know, what we've known for a long time is that older adults need an interconnected -- I didn't say integrated -- interconnected care and services across a continuum. So when we look at where we're going to invest and what we're going to do, you have to look at this and kind of widen the lens.

Secondly, most seniors want to stay and age in their home, so this is an opportunity for us to actually get very good response with the changes

that we could be putting in place.

And thirdly, unsurprisingly, because of the way our funding has been positioned, we have a high proportion of older people living in residential care facilities that, in fact, could have been cared for in their home environment if we, in fact, expanded and looked at the program in a very different way.

So what I hope today to talk about is actually hope for seniors and, in fact, how to move forward versus I know sometimes all we do is talk about the negative things and, you know, never move to, so what should we do about it, so this is, I think, a good way to at least begin.

If I leave you with one message that's important in this whole conversation is that if we're really trying to change the system with investments, we have to think about the long-term care problem as a system problem, not a sector problem, and we have to actually think about that system as an integrated community-based care for seniors.

In other words, if long-term care is not just about buildings -- long-term care needs to be not just about buildings and beds. It needs to

be about people, their home, and the communities. And we need to, as we look at the problems, in the bed, long-term beds, we have to at the same time look at investments in the other areas that are critical.

So speaking of beds and buildings, I thought I'd share a little bit about the 2008 report that, quite frankly, everybody has interpreted it in 50 different ways other than really what I said, so it's always interesting to write a report and then see it manifest itself in an interesting way of what your recommendations really are.

But the key focus was to look at staff capacity for better care and how this related to quality of care and accountability. Those are the two things that actually the independent review was to be considering and contemplating.

There was a real focus on minimum standards, and I had difficulty with that terminology from the get-go because I thought it speaks to the persistent undervaluing of older adults when we talk about minimum standards. It just seemed bizarre, and I always had this, sort of, analogy when you get your brakes done, you

don't walk in and go, you know, could you give me the minimum intervention to fix my brakes? You know, you usually would go in and say, you know, what's the premium kind of service? So it -- I always had trouble with the terminology, but above and beyond that, when there was real pressure to come up with provincial standards, I did not recommend the four hours of provincial standards.

What I did recommended was that there was more staffing and funding that was definitely needed and recommended provincial guidelines and that they be designed to achieve up to four hours of care back in 2008 because I realized that the four-hour standard was too simplistic with all of the variability in homes, that the design of the homes, the case mix, the leadership, so many of those things had huge variability. And I had actually determined that clients had everything from one to six hours of care that they required and needed.

And when I looked at those guidelines, there were two important pieces that I said needed to take place. One, there had to be local planning, so it speaks to the issue of customizing and making some sense of this. If not, it's only

going to be a numbers game. We've got the four hours, check. But local planning to enable all of the stakeholders, the residents, the staff, the operators, and the owners to come up with, in fact, how best to allocate the resources, how best to use those hours of care. And we actually created a really very good staffing playbook for homes to use. That was never implemented.

Additionally, it was critical that there be annual evaluations, and rather than such a fixation on all of the compliance and regs, but to really push annual evaluations with a good scorecard that would validate that the funding was actually addressing the resident care needs and to inform decision making and staff enhancements.

So there was a fine difference between minimum standards and guidelines but a very specific process that I wanted to recommend to suggest this thing constantly needed to be examined. And it wasn't a simplistic, sort of, pathway, these are the hours and this is what you do.

So the good news is 12 years later, we've come up with the same suggestions, but I am fearful we'll go back to, sort of, more focus on

the numbers and hours of care and not enough focus on are we meeting the needs, are the residents getting the outcomes, and is everyone satisfied with the care that we're providing.

So let me now move into the pandemic and, sort of, from both the home care and the ALC point of view, some observations. As we all know in March 2020, with the lockdown and as we continue, and rightfully so, real concern about hospital capabilities, ICUs and vents, critically important.

But I think that there was some shortsightedness not only in looking at how it was necessary to have a community-system approach to what we did but also to build on what we know from the research and the evidence. And I'm going to talk about the ALC, and I'm going to talk about the home care to expand a little bit.

From an ALC point of view, we know that from March to early May, roughly 2,200 ALC patients were discharged to long-term care homes or retirement homes. And we know that these settings quickly became the epicentre of the crisis in Ontario. Also troubling, I think families certainly felt pressure that they didn't have a

choice. They had to move people into the long-term care facilities.

Now, remember the thesis was absolutely right. You had to get capacity in the hospital, and you had to get these ALCs out of that system. Where I think it was flawed, to my knowledge, none of these patients were discharged home. Could they have been? Research suggests absolutely, yes. Not all of them, but many of them could have been discharged home.

Why do I say that? Well, before the pandemic, with CIHI data, one in five seniors admitted to residential care have actually similar needs as individuals being supported in the community. Also, a very high percent, probably well over 30% of ALC patients waiting for long-term care could be cared for at home, certainly not with our current home care program and the design of it, but, in fact, if we changed some of the home care that exists.

Actually, this is another very interesting finding: The biggest factor influencing whether patients are assessed to go to long-term care facilities, which I find that's really that surprising when you understand it --

it's not related to the cognitive impairment nor living alone nor the wandering behaviour.

What seemed to be the key switch that had everyone assessed they needed long-term care facilities was actually being assessed in the hospital setting by hospital personnel, and that was, again, CIHI data.

So now, let's talk about what happened in home care which is, sort of, I know more about home care than I ever wanted to know is one of those things. But just to, again, present the context for home care, very, very similar to long-term care. It's been underfunded over the years, not well understood. The model of care has been challenged. It's a task-oriented, almost fee-for-service model in particular in Ontario, and there have been many reports talking about the need for change, modernisation, new funding. So that's the backdrop of what was happening.

Okay. Put that with, for some reason, the thesis, again, was that need capacity in hospitals, going to discharge everyone to long-term care, going to actually shut down home care, and then we'll have freed up capacity for the home care staff to actually get into the long-term care homes

even though research from other countries was saying that was very problematic. Primary care and home care when that was, sort of, compromised created even more of a bottleneck into the system.

Well, 70% of the first assessments -- you have to be assessed to get onto home care in Ontario -- there was a decrease of 70% of those assessments, so people were not able to get onto the new home care or old -- old home care program, and the visit volumes decreased by 27%. And this is probably in a span of, like, two to three weeks.

And I think people generally initially were fearful even though -- it's funny -- the whole world was saying stay at home, one would have thought, healthcare we should have had the same kind of thinking. But I think people initially -- and our staff were a little nervous to begin with, but then when we saw what was going on in the congregate settings, many people wanted to make sure or look at the option for their loved one to remain at home.

So while this, though, was happening, we did have a lot of people who have chronic illnesses certainly having some challenges, and we did have a lot of people with end of life who would

have preferred to die at home with their loved one. It wouldn't have fallen into the same situation that it did in the long-term care homes.

Interestingly enough, though, and this, again, hasn't been, kind of, well-publicized or understood, that surprisingly, the community and the home-care program actually responded quite positively with the pandemic. We saw nothing of the same infection spread or rates of death in the home environment.

And, you know, I've thought about that a lot to say, well, what was different? And I think -- and this is just my own experience years ago as a visiting nurse, I think there's a natural orientation toward IPAC in the community just by virtue of visiting homes, et cetera. I think there was also a real spunkiness in home care, like, resourcefulness where many of us pulled out all stops to get our own PPE. So we didn't get to this, we don't have PPE. I know that for a couple of weeks, all of us were calling around and were able, actually, to get our own PPE supplies.

We moved to universal masking and eyewear very early on, actually, ahead of the guidelines. And so as a result, our infection

rates were remarkably low. Public Health doesn't actually provide this data in a sector-specific way, but for large home-care providers, we looked at our data to see the infection spread amongst our staff, incredibly low, well less than 1%.

So, I mean, that's an interesting component to look at, could we have saved some of these people if they had been discharged home?

Now, when we look at the implications for these volume changes with the home-care providers, as you can well appreciate, as with any other part of industries where their volumes decreased to that extent, surprisingly, rather than have all this capacity build up, because the business model was different, when there was no revenue coming in and a 50 to 70% drop, all of the frontline employees, thousands, thousands, went off on a leave of absence. SE Health alone, we had 2,500 go off on leave of absence. And, of course, this was exacerbated by the CERB support that our staff had.

So it created significant destabilization early on, and only now, we're actually beginning to get back to pre-COVID, but it's challenging because there were also pressures

to support the long-term care homes, and so we had both things happening. We had all the destabilization in the home-care space, and there was great difficulty redeploying our staff to the long-term care facilities because they simply were not there. There was not the capacity, and actually where there was, which was helpful, is that's where the hospitals were still funded in the whole way and with less, sort of, reduction in their patient care, they were able to move over to long-term care.

What other provinces actually did in home care is they actually funded the agencies as a whole, and that did create -- you were able to keep people employed, and it did create the capacity for both home-care services and to help with the long-term care sector.

So it was a significant lesson for all of us to learn, with this pandemic, what not to do in this particular sort of area. As we --

COMMISSIONER FRANK MARROCCO (CHAIR): Can I just ask you a question? This keeps coming up, of course, you know, the number of staff that stopped reporting for work. And as you've been -- described, your situation, it wasn't so much safety

or the lack of personal protective equipment as it was the CERB, so you can get that money and stay home.

SHIRLEE SHARKEY: Absolutely. Absolutely.

COMMISSIONER FRANK MARROCCO (CHAIR): So I got that that was -- you have a similar perception.

SHIRLEE SHARKEY: Absolutely. If we had been funded differently, we would have been able to keep these people employed, and they would have continued working.

The CERB really affected, I would say, our personal support workers because pretty much what they could get on unemployment is what they could get if they were working certain hours. Nursing was a little bit different, and a lot of the nurses left because there simply wasn't the work. And with our business model where you're not funded collectively as a whole, it's like any business, the revenue goes down 50%; you have to adjust for your costs.

And so not only do we have frontline that we had layoff, we actually had, within our whole leadership team, all kinds of adjustments

that had to be put in place for two to three months 'til we got on the other side, so really destabilized the sector. And I don't know if there was actually logical thinking to say, well, we're going to shut this down, and we're going to do this and do that. It just sort of happened, which is, I think, an interesting reflection to think about because while this was happening, I remember reading in New York and in Spain where there was a lot of discussion that you can't possibly get over this unless you continue to keep the community supports functioning and in particular home care and primary care.

And I remember while this was happening, I was very vocal to look at what's happening in other countries right now because we're going to create a big problem. And exactly what happened in other countries happened here, a real problem in the congregate settings and in the hospital capacity.

And, I mean, a lot of reasons why people were safer in their home is they didn't have the same environment for the infection spread. And I also think if we had leveraged the home environment in a different way by supporting it and

funding it and basically keeping the doors open, it might very well have helped with fewer deaths.

COMMISSIONER JACK KITTS: Shirlee, can I just ask a question about the process, then, for the CERB because none of these workers were laid off, and all of them are declared essential services. Does that allow them to qualify for the CERB?

SHIRLEE SHARKEY: Well, they were -- because our volumes went down, we didn't have the work. We did not have the work. Now, we had -- so it's a good -- I think they went off on leave of absence. We actually had some of our -- this was our -- not our direct staff but our overhead staff, they were actually laid off and qualified for unemployment insurance.

Front line, were on -- it's a good question whether they were on a leave of absence or we -- or laid off. I'm not sure how we -- I think most went on a leave and then applied for the CERB, our frontline because there simply wasn't the work.

COMMISSIONER JACK KITTS: But very shortly there was when the -- when the long-term care homes needed PSWs, and I understood there was a shortage also in home and community care, so

there's --

SHIRLEE SHARKEY: Yes. And two things were happening at the same time. I think we've almost had everyone come back, but it did come back in stages. There was certainly the school program where workers had children at home, so there was that component that played a role, and I think you have to keep in mind the context that I presented at the first was home care had previously a PSW problem and has had -- well, let's call it labour problems as relates to the funding and the resourcing, and it's been constantly, probably for the last 20 years, a real challenge to retain and recruit and keep, so you had that happening all at the same time.

COMMISSIONER JACK KITTS: Okay. Thank you.

SHIRLEE SHARKEY: But I think you're right. Most of us as providers started to look at, okay, what can we do? You know, how can we -- how can we help with this? And actually, just looking back, Jack, your question's right. We didn't -- there was no frontline layoffs. You're absolutely right. They were all leave of absence, and then within that, they were able to qualify for the

CERB.

COMMISSIONER JACK KITTS: Right.

SHIRLEE SHARKEY: But we did have layoffs, as I say, at the clinical level, management level in order to get our costs adjusted with those volume reductions.

But what was happening during this time, we said we've got to help out here. What can we do? And, you know, is there a way we could build capacity knowing that the long-term care system and beds, you couldn't -- wouldn't be able build these beds overnight -- and started to think about, you know, we've been looking at alternatives in the community for people to stay home for a number of years. And this is where Justine comes in because we started to look at, is there -- could we be pushing this whole long-term care at home or other options for people even while we're going through this so that at least, while we're in this crisis and the beds are not available, we have some alternatives, because we were concerned the hospitals were going to fall into the same problem with the ALC, and we've got the vicious circle all over again with Wave 2.

So I am going to turn it over to

Justine and to talk about a lot of the work that we've been doing to really understand the need to have more options for people. Certainly, the pandemic is one thing, but we've got this opportunity to get on the other side, and if all we do is look at the long-term care bed situation, it's going to create the same problem that we've had for 30 years.

So, Justine, over to you.

JUSTINE GIOSA: Right. So going back to Shirlee's earlier comments, the starting point for our research on the long-term care of older adults is to think about long-term care, again, as a system and not a single sector, so extending our thinking beyond buildings and institutional beds to prioritising people's needs in their homes and in their communities and bearing in mind these two very well-established points that Shirlee's already made: Number 1, people want to be at home; and Number 2, there are unmet needs and capacity issues in both home care and long-term care.

So our goal with the research is to develop and help to operationalize a new model of needs-based home care for older adults who are at risk of going into a long-term care home at some

point in their lives. And our aim is to strengthen our home-care offerings to give older adults more options to where to live and receive care as they age. We want to build a whole continuum of services to meet their whole-life needs and make home the default trajectory.

So this work is funded and led by SE Health, as Shirlee mentioned, in partnership with experts at the University of Waterloo and interRAI Canada. And, essentially, we're using a data-driven approach to accomplish three main things: The first is to really understand the needs of people receiving home care. The second is to compare these needs of people at home to people in residential long-term care; and the third is to really develop and operationalize life-care packages so that the home care sector can better meet those needs.

So I'm going to start with the first which is understanding the needs of people at home. We completed an historical analysis of over 205,000 Ontario home-care assessments using standardized, routinely collected interRAI home-care data, and we did a market segmentation of this population into six categories of individuals at risk of long-term

care admission. And we found that about 80% of long-stay home-care clients, so that's some 160,000 people, are considered at risk of long-term care placement based on known medical, functional, and psychosocial predictors. So these are things like social frailty, caregiver distress, chronic disease, cognition, behaviours, and medical complexity. And we also did further descriptive analysis on these categories which revealed that about 35% of the Ontario home-care population has mental health, medical, and functional needs combined.

So this means that we need more than just medical care. We need what we call full-life care which considers health not just as absence of disease, but living well as possible under any circumstances. So, yes, we need medical care, but we also need mental well-being, societal participation, and daily functioning.

A one-size-fits-all approach does not work to address the breadth and diversity of the needs of the older population, and an understanding of this is really required to break that Groundhog Day loop that Shirlee was mentioning earlier. We need different services in home care, not just more

of the same.

The second thing we did was to compare the needs of the people at home and home care to the people currently living in residential long-term care. And so we did an historical analysis of over a hundred thousand Ontario long-term care assessments using that same routinely collected standardized CIHI data.

And we mapped the six categories of the home-care population considered at risk of long-term care admission to our current long-term care population. And what we found was around 93% of the long-term care population in Ontario mapped to five of the six categories that we used to describe the home-care population.

So what's most notable about this was that 38% of the long-term care population actually falls into the category that we most serve in the home-care sector. So this means there's significant overlap between the needs of the individuals who are receiving care in long-term care and those receiving care at home.

So not everyone in long-term care requires 24/7 PSW services, and not everyone in home care just needs a bath. So we really do need

to get creative and have new thinking about how to care for these people in new and creative ways and prevent or delay their admission to long-term care homes altogether.

So the third thing that we're doing, and it's in progress, is that we're really committed to taking this beyond a conceptual concept, and our goal is to really support the operationalization of this model, so we're working in partnership with home-care leaders, clinicians, point-of-care staff, patients, and families to codesign new life-care packages for home care to meet these needs.

And what we're finding so far is that life care involves access to more than 65 types of services and care in the community from a range of interdisciplinary and multisector providers anchored by home care. And so this is a stark contrast to our existing models.

We're also working to compare our existing model to existing models of care -- or sorry -- our emerging model to existing models of care. We're doing an in-depth review of historical LHIN service utilization data to understand how our emerging model compares to current LHIN offerings.

We're reviewing new high-intensity support programs in home care, and we're also working to better understand the fully loaded costs for current residential long-term care beds which requires thinking more than just about the per diem direct care costs but also thinking about external factors like caregiver support, social interaction, and care coordination to name a few.

So overall, what we're learning is that long-term care home admission risk goes beyond thinking about the current waitlist or ALC population. Social frailty, caregiver distress, and mental health are hidden risk groups that are often one hip fracture away from a crisis placement to long-term care, and we can do better for them at home. And a new model of home care to support older adults at home and help them avoid long-term care admission requires an optimisation approach, not a substitution model. We can't just have more of the same home care, and we simply can't just repurpose the current per diem costs of residential long-term care to the community and expect change.

So our research will help us understand not only how to better support people in the community but also what beds are needed for what

populations.

And so now, I'm just going to turn it back over to Shirlee to wrap us up.

COMMISSIONER JACK KITTS: Can I just ask a question before you turn it over?

JUSTINE GIOSA: Sure.

COMMISSIONER JACK KITTS: So in your study, I want to see if I understood what you said. So 80% of people in home care are at risk to move into long-term care. They've got the risk factors that would suggest that someone might look at them and say you need long-term care. Is that --

JUSTINE GIOSA: Yeah.

COMMISSIONER JACK KITTS: Is that what you -- the second thing you said you -- a hundred thousand people -- residents in long-term care you studied, and 93% of them, of that population, matches in risk factors to people who are being cared for at home --

JUSTINE GIOSA: Correct.

COMMISSIONER JACK KITTS: -- or five out of six, I think you said --

JUSTINE GIOSA: Yeah.

COMMISSIONER JACK KITTS: -- of factors. So I think if you studied the patients in

hospitals, in hallways, or ALCs, you'd probably find a similar overlap.

SHIRLEE SHARKEY: Yeah.

COMMISSIONER JACK KITTS: And, Shirlee, you'd agree. So my question is, you've got three very similar populations of patients; it would be hard for someone without a study to figure out which one is long-term care, home and community care, or subacute hospital care.

And so that's a -- that's a large number of frail elders that we have, and you've shown that the decision to where they go is very narrow because they're all very similar.

So my question is, you know, in your opinion, the goal is to get the right care in the right place at the right time.

With such an overlap, how do you decide which one of those three places is right? And even if you do decide, just one -- you say one fracture -- I'd say one cold away, they move to another level of care and then back.

So you're right. This has to work as a system, and it has to be seamless so they can go back and forth, but I've never been able to really figure out who is the decider as to where they go

and then where the resources are put? Who is that decision maker?

SHIRLEE SHARKEY: I think it's a really good question. And what is another piece that we haven't added is the decider, ultimately, should be the client and the family because, you know, a lot -- especially when we talk about the life-care needs which are broader than the medical-care needs. You know, sometimes, medically, Jack, it's a no-brainer. You need to go listen. You need to be in the hospital. You need to have the right diagnostics; here's the intervention.

But so many of these people with chronic disease -- the only thing I would suggest when you asked Justine the question, these people need long-term care; I'm not sure I agree that they need. We have identified that they have needs similar to long-term care, but they may not need that institution.

And you're right. It's an economic issue to some extent. It's a caregiver and family issue to some extent, and then it is a health professional all, kind of, talking to figure out where and what makes sense.

And the big challenge has been right

now, the choices are very limited for people, and our first starting point is you need to go to a long-term care facility. And I think that's problem Number 1.

I think you're right, I don't think we'll ever get it straight where who -- one, who is making the decision? It typically is the family members who are making the decision based on the input.

But also, if we don't give them options and look at, you know, where and what and how makes sense and design those options, we will continue to flood the hospitals, and we will not be able to build enough long-term care beds with the population.

I think that we're not addressing actually what people want. People want to stay in their home and age in their home, and the majority want to die in their home. And we've not designed the system to make sense of it, and so who, ultimately, is making the decision most of the time is actually the health providers influencing the family to make the decision, and I think that's flawed.

I think the health provider should be

figuring out how to design the systems. We have all these options. Because your point's an absolute correct point. They could be in a hospital, in a long-term care facility, and in their home and be thriving or surviving or dying, one of those three. And it's much more complicated to help people understand their choices and for us to create and design the system that allows that to happen, and I think that's where we -- that's the biggest flaw right now.

COMMISSIONER JACK KITTS: Well, can I follow up, then, because your -- in your opening comments, you said that what we need is a system, but you made a point that it's an interconnected and not an integrated system.

So when you've got three healthcare organizations involved in almost an identical patient and where they could go, I'm curious because I think you mean interconnected is a partnership model with separate governance and separate funding, whereas integrated would be an integrated model with integrated governance and funding.

And so I'd like to -- I'd like to learn more about how the -- at least the three key

players in this way could function and be successful in an interconnected model.

SHIRLEE SHARKEY: Yeah, it's a good -- I'm not surprised you picked up the difference in that terminology, Jack. You never let me get away with anything. You just, sort of, slide it through.

I think people -- we need to design the system so that we are intersecting with people's lives, not that their lives are intersecting with our amazing integrated system. And that's why I say, if we -- if our starting point is the -- is the eyes and ears of the family and the individual, the issue is that they, then, get to a system that is connected for them. It may not necessarily be that that system works best. It may work best for us from an integrated point of view, but for a family, it may be a very different model that's required.

Sometimes an integrated system could work. Sometimes, just as Justine talked about, life needs may impact hundreds of agencies, small, big, large, community, et cetera. And the issue would be to design it so people can connect with that, not that we connect all of these agencies in

one integrated way.

I think from a medical health point of view, integration makes a lot of sense because it's expensive; there's a need for exchange of information. When we broaden this for the chronic population and it's life care, that model needs to look very different, and there needs to be flexibility within that, and we need to figure out a process that allows that to be flexible.

So, you know, one -- I just think we've got the silver bullet thinking of everything will be integrated -- like, we will be integrated, and it will make everything okay. I think it needs to change around to people will have all of these things interconnected to meet their needs however they're manifesting themselves.

And again, it's just a different starting point with seniors, with the variability that exists, and with life care which is much broader than the disease process.

COMMISSIONER JACK KITTS: Okay. Thank you.

SHIRLEE SHARKEY: Does that help clarify that?

COMMISSIONER JACK KITTS: Yes, putting

it to the patient and family connection as opposed to the caregivers, so.

JUSTINE GIOSA: In our research, we use the definition of integrated or interconnected care from the NHS which is the user-led definition of integration which is, I can plan my care with people who work together to understand me and my care, or has put me in control, coordinate and deliver services to achieve my best outcome. So it really is putting them in the driver's seat.

COMMISSIONER JACK KITTS: That's excellent. So one's a viewpoint from the caregivers and the other from the patient or client, so thank you.

SHIRLEE SHARKEY: And it doesn't mean that one is right and the other is wrong. It, again, is how we actually, then, design that to work effectively because you're absolutely right sometimes, Jack. It does make sense things be integrated, and we get capacity, and we get specialization.

But that doesn't mean that's how it should be designed for the end user necessarily, and I think especially with the seniors population, our challenge of figuring out how to be customized,

personalized, and design it different, that is -- that is our biggest flaw, and because the rest of our health system is trying to use pathways and standards and continuity and linear thinking and, you know, very, very specific things because the environment is controlled, that changes up in this other environment which creates havoc when you're trying to have funding and policy and different ways of looking at it. But if we get it all organized and we don't get any better outcomes or better value, what did we actually accomplish with this?

So maybe to summarize -- I know I had another thought when you asked me that question, Jack, and I can't remember what it was, but anyway.

COMMISSIONER JACK KITTS: Okay.

SHIRLEE SHARKEY: So from, sort of, a conclusion, I think what something we need to be thinking about for our starting point is that certainly, Canadians and certainly Ontarians are no different -- overwhelmingly, they want to live and age and die at home. This is a wonderful opportunity for us to capitalize on, and there's been all kinds of studies that talk about this.

But we haven't designed the system to

actually address what people want, and that does baffle me sometimes. I go, well, it's an easy thing to be looking at; this is what people want, and how do we design? And that does not mean that there's not a need for long-term care facilities, nor does it mean that acute-care hospitals don't play a role. They certainly do. It does mean it's a different starting point.

What we also, I think, can conclude is that home care is certainly one of the safest settings for healthcare delivery during this pandemic for the frail elderly. Certainly, with the infection rates and with the home-care staff and clients remaining exceptionally low, this is something for us, I think, to certainly think about as we go forward if there is, hopefully not, another pandemic to make sure we keep community services robust and thriving if even to help build capacity to help other parts of the sector. That would have been, in itself, extremely helpful in this space.

If we had a different approach to dealing with people in their homes -- and this is, I think, the biggest takeaway for me -- the number of beds we actually need for the future is unknown

right now. And I am convinced we would need fewer beds, and I also am convinced we'd have happier seniors because they want to remain in their home. And so I think we have to do a little more work to actually understand what capacity we need in what areas and then how we need to change that up.

But I think what's probably fundamental in any change is a new way of thinking, and you can see from these conversations where just our starting point is different. And then what changes need to be put in place, talk about new ways of thinking and working, and I think that's the only way we're going to escape the loop.

My concern right now is with the recommendations to improve the long-term care homes is important, but once again, it's been discussed in isolation. And once again, it will probably create havoc to the home-care system, and you will pull all of the resources that are already stretched and with challenges to the long-term care system. So we've done the full loop. There will be less options for people to be in their home.

Go ahead, Jack.

COMMISSIONER JACK KITTS: I'm just -- is there -- is there any likelihood that the

leaders in the long-term care sector, hospital sector, and home and community care sector get together to figure out how we keep -- stop robbing Peter to pay Paul and work as a system, an interconnected system?

SHIRLEE SHARKEY: There certainly should be, Jack. I think the problem is everyone has a different starting point. The acute care has a different starting point, and it's right. People in their homes, I would suggest, that's the paramount starting point when we look at seniors demographics, what we're going doing; and the long-term care facilities also have a different starting point.

But you're absolutely right. We have to come together and look at this as a system, but I would -- I would even challenge; we actually have to over-rotate on community-based support for people. Why do I say that? When I go back to the C.D. Howe statistics, we are underfunding services for seniors, period. And the percentage that's going into how they live their lives and where they live their lives in their home is a small segment.

Now, I can just speak to home care. Home care -- and I think in the 30 years I've been

in home care, it still is roughly 5% of the total public expenditure within home care. Now, but here's the kicker: Probably only a third of that actually goes into direct care in that we've structured it in an interesting way with lots of layers and assessments that, you know, people are actually not getting as much of that money in direct care. And the other thing is -- we've talked about, is we probably need a whole different approach to the care. There can't be service limits, and it can't be just, you know, do you need wound care? Great. You get home care. It has to be looked at in a much more life-care way to keep them functioning in the community differently.

So you're right, Jack. The three -- the three groups need to come together, but the three groups have to agree to what's the starting point for all of us versus in each sector, what's the starting point.

COMMISSIONER FRANK MARROCCO (CHAIR): How do you react to the assertion that we constantly hear that the resident in a long-term care facility is in their home? It seems to be a rather institutionalised home.

And I'm curious whether you think the

terminology is causing part of the problem because you want them -- you say they should be -- that they want to be at home, and they're better served at home. And the long-term care facility is saying, this is their home. And it just -- you know, it's a funny home where your loved ones can't come to visit you. You can be confined to your room for an extended period of time, et cetera, et cetera.

And so I just wonder have -- what you think, whether that has occurred to you, whether you think that's, in a sense, part of the problem?

SHIRLEE SHARKEY: It is. I'm wondering, Justine, some of your thinking with that.

Because, I mean, I think you're absolutely right. How we define one's home is an interesting phenomena. But, I mean, most people, when they say they want to remain at home, it really is about their independence, control, and management of their life which we all -- we all have at every point in time.

I think the long-term care facility and, you know, residential care, it becomes where they happen to be living based on their condition

as I would see it. But, I mean, I think you're right. Some -- in many ways, terminology we use, especially within the senior's population, is a challenge. And I would suggest, firstly, minimum standards is terminology that I find difficult.

I would not want anyone to say to me, here are the minimum standards of what I'm providing to you. Just when you really think about that language, it helps us ponder how we've moved into that thinking.

But, Justine, you may have some other thinking, so jump in.

JUSTINE GIOSA: Yeah, I think it goes back to thinking about congregate living settings, and I think prepandemic, you know, some of the things I talked to about being predictors for long-term care admission that are less-often talked about are the social frailty piece, the mental health piece, and the caregiver distress piece. And I think those have been exacerbated in long-term care for various reasons during the pandemic because of lockdown and quarantine and all those things you just mentioned. But pre-pandemic, you know, being in a congregate environment, those things you can't discount, you know, someone going

to a dining hall and having that social interaction if they get it. So in some cases, that's good. So it is home-like, and the intention is to be home-like.

So I think when we think about what life care looks like in the community, we can't forget those things as being part of what being at home requires and what people's needs are in terms of their social interactions, in terms of caregiver support, in terms of their mental health.

And so I think when we think about home, it has to be not just about the medical piece, but also about all those other factors. And so in a congregate environment, some of those things do happen under non-pandemic circumstances.

COMMISSIONER FRANK MARROCCO (CHAIR): Well, I was just struck because Ms. Sharkey used the phrase, facility. And when you call it a long-term care facility, I think you're making a distinction between that place and a person's home, but the -- but the institutional terminology is that it's the person's home.

SHIRLEE SHARKEY: Yeah.

COMMISSIONER FRANK MARROCCO (CHAIR): And I think that confuses -- I was just curious

whether you thought it confuses entirely the discussion.

SHIRLEE SHARKEY: I think it sometimes does, and, you know, I just go to the old adage, I mean, there is no place like home. And I do think some of these other options are home-like, but they are not home. But I think you're absolutely correct. It sometimes confuses, and I think some of it is almost how to label it or brand it in a more acceptable way for people.

I think the other thing we haven't talked about with long-term care, which is another thing to think about, is a lot of people who are going into long-term care, there are the financial issues. And that's typically why the decisions -- you know, Jack, when you talked about, when you have people look a certain way in acute care and in the community and in the long-term care, and they all look the same from, sort of, a functional, a medical, et cetera, many times the issue is, in fact, the financial situation.

And that's where we also, in addition to looking at this in a system, is looking at very different alternatives for housing. Also, looking as a system is what are some of the other tax

incentives for people to, you know, want to look at other options to keep people at home. So it is a complicated analysis that I can understand. It makes people's heads hurt and go, could you just make this simple for me and let me solve one little part of this problem. But by solving one little part of the problem creates the ongoing -- the years and years of difficulty creating options for people. And right now, with the growing demographics, time is not on our side, and we do have to change things up.

And I don't know, Jack, if we can do it fast enough by bringing together the three sectors and having conversations because that has been happening now. I mean, I was -- I was just on a panel and somebody was saying, Shirlee, for 25 years I've heard you talking about this. And I thought, okay, so we clearly need to start doing something different. And I think we do, and it maybe is -- for example, we have an overhead that we didn't bring up, is even rethinking long-term care bed capacity.

And here's a thought: We have an illustration that shows in a community with homes, every home has a bed, so it actually is saying,

here is our long-term care capacity, and it shows all of these additional beds above and beyond what an actual facility would be, but we are creating long-term care capacity in the community by doing things entirely different.

So above and beyond the announcement of actually new beds being built, why not allow -- announce a whole different approach and option.

Now, I understand there are all the implications for where do we get the resources? What does this look like? But if we don't begin to get in front of this, it's unsustainable.

Economically, what we're proposing here is unsustainable. Add to that, it's not what people want anyway, so you begin to ask yourself the question, what's the problem here to move forward differently?

COMMISSIONER FRANK MARROCCO (CHAIR): Well, thanks very much. Oh, sorry.

COMMISSIONER JACK KITTS: Thank you. Just one more question, and I don't know if it's a question or a request, but I like the research and your report on your findings in terms of understanding the needs of people who are in long -- in home care now and those in long-term

care.

My question is, are you planning to do more follow-up research to learn where, of those three places, the outcomes or the, I guess, the experiences is best as given by the patient, and it's more -- more asking for standards of -- I don't know -- satisfaction or experience with the three places given that they could be in any one of three?

JUSTINE GIOSA: Yes, absolutely. So this is a work in progress. We're part of the way there, but we do plan to sort of operationalize this model and then also seek further input beyond the home-care sector in terms of referral patterns, in terms of how those people might access services, and how we might move forward in operationalising this type of approach. So absolutely, we -- and we will be publishing these findings. They're quite preliminary, and so we will be putting those out there so that we can share them more broadly.

COMMISSIONER JACK KITTS: Excellent.

SHIRLEE SHARKEY: I think you're asking a really good question, what value are we creating? So where can we get the best outcomes with the clients' satisfaction, and client being client and

family satisfaction, of those outcomes over cost. And that's where I think you're absolutely right. We need to look at that and say, all right; how do we design that that really accommodates the greatest value for how we're funding services for seniors?

The only thing I would suggest is, and I know it drives me crazy when everyone goes, you know, other countries are doing this. But other countries are doing this, and they seem to have a better handle on care for seniors. And, you know, how do I gauge that? I simply say when I visit them, boy, I would like to be aging here than in Canada. And that's where I think -- that's the real, I think, measure is, as Canadians, is this where we want to age and where we feel the most comfortable that we'll be able to age with the dignity we're looking for.

And right now, it's not looking good, and I'm the most positive person you could imagine, but right now, I would say it's making me a little nervous to how we'll get on the other side of this.

COMMISSIONER FRANK MARROCCO (CHAIR): Well, thanks very much for, you know, helping to develop this notion of more care at home than --

and slowing the transfer of people to a facility. It's something that has come up in our discussions, and this has fleshed that out a bit more for us and considerably more for us. And so thank you for that. And thank you for the presentation, and you may hear from us again.

Oh, sorry, Commissioner Coke.

COMMISSIONER ANGELA COKE: No. No. I just wanted to say that I do very much appreciate your choice of words because that helps people reframe their thinking about things. So even the word life care means something very different than just being narrowly focused on medical care.

SHIRLEE SHARKEY: Yeah.

COMMISSIONER ANGELA COKE: So I think, like you say, if you want to reorient the way people are looking and thinking about things, you have to think of the different language that helps people do that, so I found that very useful in terms of how you're suggesting a way more holistic approach. And I think the reason we don't have that view, fundamentally, is because of the devaluing of seniors. And I think if we had put a different value on them, we're going to think differently about the type of broad care that they

need. It was very helpful. Thank you.

SHIRLEE SHARKEY: Well, and thank you all. I know it's a -- it's a complicated area, and I can't tell you how much I appreciate the -- you know, the depth and the work that you're doing in this space because it is -- it is so critical, and even though I do criticize a number of reviews and expert panels and everything, I'm hoping that we can -- all of these do eventually get to action which is exactly what we need.

So, you know, I appreciate you're commitment to keep the course with this, stay on the course with this.

COMMISSIONER JACK KITTS: Yeah. Thank you.

U/T SHIRLEE SHARKEY: We're happy to provide any other information or any follow-up or any more of our research work. We'd be honoured to provide that to you.

COMMISSIONER FRANK MARROCCO (CHAIR): Thanks very much.

COMMISSIONER JACK KITTS: Thank you.

COMMISSIONER FRANK MARROCCO (CHAIR): Bye-bye.

COMMISSIONER ANGELA COKE: Thank you.

SHIRLEE SHARKEY: Bye for now.

COMMISSIONER JACK KITTS: Bye.

-- Adjourned at 10:00 a.m.

REPORTER'S CERTIFICATE

I, JANET BELMA, CSR, Certified Shorthand Reporter, certify:

That the foregoing proceedings were taken before me at the time and place therein set forth;

That all remarks made at the time were recorded stenographically by me and were thereafter transcribed;

That the foregoing is a true and correct transcript of my shorthand notes so taken.

Dated this 22nd day of December, 2020.

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