Long-Term Care COVID-19 Commission Meeting

Bilingual Group Meeting with Families/Loved Ones
on Friday, February 19, 2021

77 King Street West, Suite 2020
Toronto, Ontario M5K 1A1

neesonsreporting.com | 416.413.7755

MEETING OF THE LONG-TERM CARE COVID-19 COMMISSION

--- Held via Zoom Videoconferencing, with all participants attending remotely, on the 19th day of February, 2021, 1:00 p.m. to 3:00 p.m.

BEFORE:

Angela Coke, Commissioner
Dr. Jack Kitts, Commissioner

PRESENTERS:

BILINGUAL GROUP MEETING WITH FAMILIES/LOVED ONES:
Participant 1
Participant 2
Participant 3
Participant 4
Participant 5
Participant 6
Tiffany Fearon, Family Councils Ontario

PARTICIPANTS:

Dawn Palin Rokosh, Director, Operations, Long-Term Care Commission Secretariat
Alain Daoust, Team Lead, Long-Term Care Commission Secretariat

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

ALSO PRESENT:
Deana Santedicola, Stenographer/Transcriptionist
Louise Côté Limbos, French/English Interpreter
Nathalie Bédard, French/English Interpreter

-- Upon commencing at 1:00 p.m.

DAWN PALIN ROKOSH: So good afternoon, everyone, and welcome to this bilingual meeting with the Long-Term Care COVID-19 Commission and family members and loved ones of long-term care residents from different areas of Ontario.

My name is Dawn Palin Rokosh, and I am a Director with the Secretariat in the Commission, and I am joined this afternoon by my co-facilitator Alain Daoust, who is a Team Lead with the Commission, as well as the following team members, Adriana Diaz Choconta and Angeline Hawthorn, both of whom are Senior Policy Advisors with the Commission Secretariat.

ALAIN DAOUST: This is a bilingual meeting where French- and English-speaking participants will be able to speak in either of these languages. Simultaneous interpretation is being provided, and participants have chosen to participate either in the English or French language channel at the bottom of the Zoom screen. Dawn will predominantly be speaking in English, and I will predominantly speak in French, and participants will be able to hear in the language

of their choice.

As you know, the Commission is led by three Commissioners, and two of the three Commissioners are with us here today.

First of all, Dr. Jack Kitts, he will be the lead Commissioner for today's meeting, and also with us today is Commissioner Angela Coke.

I would like to thank Tiffany Fearon and the Family Council of Ontario, as well as Gilles Fontaine from la Fédération des aînés et des retraités francophones de l'Ontario, and they have been very helpful with today's meeting.

Today's session is being held over Zoom. If anyone has connectivity issues, you can re-join the meeting at any time. If anyone has technical issues, you can reach out to Angeline Hawthorn via email, or also my other colleague, Adriana Diaz Choconta, who will be able to help you out.

Also, if you are comfortable turning your camera on, please feel free to do so. This session is not being video-recorded. However, if you would prefer to stay off your camera, that is fine as well.

DAWN PALIN ROKOSH: This session is

being transcribed by our court reporter, who is present on the call. The transcripts will be posted onto the Commission's website, but your names will not appear in the transcript. When you are speaking, you will be recorded in the transcript as "Participant" and then your number, so "Participant 1", for instance.

If you wish to refer to another person during this meeting, another participant during this meeting, please refer to them by their participant number, which is displayed on the screen.

Although we have ensured that you are anonymous, both in our outreach as well as in your participation here today, the information that you choose to share today will be posted to the website.

So please be aware of any identifiable stories that could reveal your identity if that is a concern to you.

Now, in terms of our agenda today, we will begin the session with some introductory remarks from the Lead Commissioner for this session, Dr. Jack Kitts, and then we will proceed to question 1.

We will hear responses from participants in numeric order asking Participant 1 to respond first and then making our way to Participant 6. We'll go in numeric order until Participant 6.

We will repeat the same process for question 2.

Once we finish hearing from all participants on both questions, we will have some concluding remarks, and we will wrap up the meeting.

In order to hear from all of you on both questions, we have asked that each one of you would speak to for up to around four minutes in response to each of the two questions.

You have all been through a great deal, and we know that we only have a limited time together, so we encourage you to focus first on conveying to the Commissioners the most important things you want them to know about your experience.

If there is something you aren't able to cover in your first speaking time, you will have an opportunity to cover it in the second.

And now I would like to call on Dr. Jack Kitts to provide some introductory

remarks.

Dr. Kitts.

COMMISSIONER JACK KITTS: Thank you, Dawn. Good afternoon, everyone. It is a pleasure for me to be with you, to welcome you today, this afternoon, for this very important dialogue.

Thank you for meeting with us today.

As Dawn said, my name is Jack Kitts, and I am one of the three Commissioners appointed by the provincial government. I am joined by my colleague Commissioner Angela Coke, and the other Commissioner, Frank Marrocco, was not able to join us today.

As you are no doubt aware, this Commission was set up to investigate the spread of COVID-19 in long-term care homes and the impact it has had on the residents, families, and staff.

Before we begin, I want to provide a bit of context about the Commissions in general and our Commission in particular.

Governments will often set up Commissions of Inquiry after a tragic event has occurred.

The purpose of a Commission is to investigate why the tragedy occurred and to make

recommendations on how to prevent it from happening again.

Most Commissions begin their investigation after the tragedy is over. In our case, we are conducting our investigation as the crisis continues to unfold. Our final report and recommendations will be submitted to government at the end of April this year.

However, we have already submitted two interim letters of recommendations to government because we believe they will help manage the pandemic as it is continuing to unfold.

Our Commission is independent of government. Our role is to report our findings and recommendations to the government. The decision to accept and implement our recommendations is the role of government.

Now, as I stated earlier, an important part of our investigation is to learn how residents, staff, and family members have been impacted by the spread of COVID-19 in long-term care homes.

So today, we are asking you to help us understand the impact COVID-19 has had on you personally and tell us what you would recommend to

prevent this tragedy in the future.

Those are the two questions that Dawn will ask you. We understand that many of you may be a little nervous about participating in this meeting, but we want you to know that we truly appreciate your courage in taking time to help us with this really, really important task.

Our hope is that the work of the Commission will help ensure that such a tragedy is never repeated, and we believe that by sharing your stories you will help the public and government understand why it is so important that this never ever happens again.

Now, before we begin, I will ask you to join me in observing a moment of silence in memory of those residents and staff of long-term care homes who have lost their lives during COVID-19.

[Moment of Silence Observed.]

Thank you. I will now ask Dawn and Alain to continue facilitating the session.

Thank you, again.

Dawn.

DAWN PALIN ROKOSH: Thank you very much, Commissioner Kitts.

So we'll now begin with the first

question, and the first question is: Please tell us about your experience caring for a loved one in a long-term care home during the pandemic. How has the pandemic impacted you and your family member? Is there anything in particular that concerns you?

I would like to start by calling on Participant 1 to share with us her experience in response to this question. Participant 1.

PARTICIPANT 1: Good afternoon, everyone. Can you hear me? Okay.

So I'll just read my short synopsis.

My parents are on different -- were on different floors in long-term care. They could not see each other every time there was isolation. Dad was so confused. He didn't understand why his wife could not visit between the floors. Isolation made my parents backslide with physical health. An example would be that dad forgot how to eat because of the lack of seeing another person eating, just that physical act of eating.

He went from, like, eating himself in the dining room area to really forgetting how to eat. So during all of the isolation, my dad must have lost at least 20 pounds, if not more. I don't have an exact number, but he went from -- you know,

he got quite skinny.

The mental health for my mother, who previously had two mental breakdowns due to stress of caring for my father earlier, she had a very difficult time with all of the isolation on her own floor, the outbreaks.

Dad died just after Christmas when my parents were finally able to visit each other again, so there was long periods of time with my dad declining. During all of those outbreaks and all of the isolation that came and went, it is very, very hard on the married couples.

So dad did not die of COVID, but nevertheless he had to have last rites by a priest during COVID. It was all very difficult. But we were fortunate we could get that done.

One thing I would like to note in my little synopsis of my parents is that the nurse came to me just slightly before and after my father died and said, If there is anything that you want to take from your father's room, please do it now, keeping in mind -- like I'll just paint the scenario. My father was dead in bed. We had said good-bye to him. And now I am having to rally myself to pack my father's room. The reason

why she said she was very sorry was that I would not be allowed back in the room because of the pandemic, the virus, the contagions, all of that.

So either I pack now while I was there, or it would be done sometime in the future by the building.

So my brother and I stayed, and we packed up my father's room while he was deceased in bed. It was very traumatizing.

So that is my synopsis.

Now I'll read you my points for number 1. The staff would often say to both my parents, "We are so understaffed", and the residents feel even more stressed during the isolation. Mom said that she would take a shower instead of twice a week, which is the governance, to once a week. So she is compromising her own care. She is trying to be helpful in a situation of helping the overworked staff, but at the same time you can imagine they are compromising their own dignity. They feel as though the staff don't have enough time because they are too overworked.

So in that case, I would say that the staff should not be sharing their stress with the residents because it just makes things all more

compromised. And it isn't just the home my parents are in. I have heard that from other friends that have had the same situation where the staff tell them that. They don't mean to be mean, but it is just --

The other point for number 1 is the Life Enrichment booking. I feel that Life Enrichment booking window visits should be done online in the future to avoid having to deal with delays to book visits with your parents, because we could make a call or an email to them and say we need to have -- we would like to have a window visit, but we might not hear back from them for several days because Life Enrichment are also running around doing all kinds of other things.

So there needs to be something set up in homes where we can book online visits ourself, whether it is a window or if it is a Zoom call with them, to book our own time slots.

The residents need more iPads for communication in general through the Life Enrichment program.

Those are my two.

And for point number 2, I found communication difficult at times between the

government and trickling all the way down to us who are the family caregivers.

So I feel that a gold standard for information and clarity and distribution is needed. When mass emails are sent, the same language is used to -- that the same language be used to all long-term care homes in the province. But before they are sent, have the emails reviewed by the heads of Family Council so that they can interpret it as a family member if they are reading this information, thinking how do I interpret that? What else can I suggest to the government, before they release the information, so that when it is read by all people, not just the government who are comprising it, but all the family members.

Because what happened was I would often have to email our Administrator back and say, Does this mean this for my scenario? And that takes time away from her important role as Administrator.

So I had several times where she would say, Let me look into that and clarify for you, because she said the language is quite broad, so in terms of my situation, how does it apply.

So I felt that before the full messages are going out by the Province or by the Commission

or by whoever, the powers that be, Public Health, go out, that they should be in collaboration with Family Council. Two different people can read differently into wording if it is not clear.

That is number 2.

The other thing for number 2 I have written down is balancing the mental and emotional consideration for all with special consideration to the married in long-term care. More resources are required for staff to support the residents. They want to support the residents, but they need more resources.

More activities for the residents during the times of isolation are absolutely necessary. One suggestion would be even if the activities are just in the doorways of residents that are isolated, just so that they can be in the doorway and participate.

I had an example. I recently played music with one of the Life Enrichment recently, and at the end of the hallway. We were socially distanced. I was playing guitar and singing along with a staff member in the building. And what the PSWs did was they wheeled all these residents into the hallways just so they could see or hear the

music. And what was very touching to me was that non-verbal -- there were a few non-verbal, completely non-verbal, residents that were actually singing songs. So you can imagine during an isolation period how needed that is, like physical human contact with residents. Others that are not -- they have no motor skills at all, they were actually tapping their feet in their wheelchair. It was so beautiful to see. It almost took my breath away, but I was singing, with a mask on as well.

Anyway, I think I have got my points covered.

DAWN PALIN ROKOSH: Thank you so much, Participant 1.

PARTICIPANT 1: Oh, sorry, one more really quick point.

My mother, who has pretty well a hundred percent cognition, she felt that the communication to the residents was lacking, at times hit and miss.

My mom had to find out updates about outbreaks from me because we found out from our Administrator through Tele-Health. So my mother was often in the dark as to the progress of it. So

that was the second one.

Okay. Thank you.

DAWN PALIN ROKOSH: Thank you so much. And, Participant 1, I just want to take you back for a second to something that you said at the beginning, because for me part of your sentence got cut off, and I want to make sure that we got it down, and I am also looking at Deana to see.

So you had said that your father forgot how to eat.

PARTICIPANT 1: Yes.

DAWN PALIN ROKOSH: From the lack of -- and I think you meant seeing other people eat, but I want to make sure we have got that down.

PARTICIPANT 1: Yes. So during times of outbreak and isolation, the residents are in their rooms, and they aren't seeing other people eating, right, because they are by themselves eating off of something similar to a hospital tray, and the eating component is so important with the socialization. Even if residents don't feel hungry, they will still eat something because they are mimicking other people eating. And so that does help sustain them in their isolation period.

So, yeah, there was absolute lack of --

and I know the staff do their best to give them a few mouthfuls of food, but it is very difficult for one PSW to feed nine people in isolation. It is so hard, you know. And they don't have time to sit for 10 or 15 minutes to coax an elderly person to eat.

So does that answer?

DAWN PALIN ROKOSH: Thank you. Thank you. That is really helpful. And I just wanted to make sure that we got that information down.

PARTICIPANT 1: Yes.

DAWN PALIN ROKOSH: Participant 1, I want to thank you very much and tell you how sorry I am to hear about this experience.

I know that you have shared with us both your experience and some of your response to question 2 because, due to a personal circumstance, you may not be able to participate for question 2.

And so let me just -- in the event you are not still here at the end, I just want to thank you very much for sharing your experience and insights with the Commission.

PARTICIPANT 1: Thank you.

DAWN PALIN ROKOSH: And wish you the very best. Thank you so much.

PARTICIPANT 1: Thank you.

DAWN PALIN ROKOSH: Okay. So I am going to call next on Participant 2, please, and Participant 2, I will ask you to -- I'll just repeat the question again. Please tell us about your experience caring for a loved one in a long-term care home during the pandemic. How has the pandemic impacted you and your family member, and is there anything in particular that concerns you?

PARTICIPANT 2: Thank you and good day. I would like to share with you my love story with my spouse in the pandemic in a long-term care home.

It became a very difficult time for our life as a couple, for the family, for our friends. My dear husband does not understand what the COVID is, what this pandemic is. We tried to explain to him, but he doesn't understand. He can't grasp the impact it has on us, on our family. His family is no longer visiting him, neither his wife, so he is experiencing isolation, fear. He feels sorrow. He has to live in his room. He is amputated of both legs, so most time he is in his bed alone in his room.

But he calls me seven or eight times a

day, sometimes even more often. He even calls me at 3 o'clock in the morning. He cries. He needs services.

The staff don't get back to him quickly enough, so I call the home. I always call the home to ask the home to step in, to make sure that he gets care.

What a difficult situation for my spouse.

And also, in 2020 we celebrated our 50th wedding anniversary, but we could not kiss, hold each other, spend time together. On the day of our wedding anniversary, I could not go in to visit him. The villa did not allow me to -- or did allow me and our children to see my spouse through a window. He was so sad. He refused to eat, to get up, to partake in any activity. Finally, he came to the window, and he was angry, celebrating 50 years of your wedding. He wants to communicate with police, with the media, with lawyers. It was very sad for us to see him from the outside go through that. It was a horrible time, a difficult time, for me who, you know, walked with him for 53 years, and difficult for my family.

But the staff -- for the staff in the

villa, in the home, it was a very difficult time for them too. They no longer have the support of the family to help them out. On July 12, I had to do a training session with the villa, and that afternoon I was reunited with my dear husband. I will always remember that happy time to be able to get back with the love of my life. My partner was no longer the one I knew, though, very frail. He had trouble speaking. He was shaking. He was lost. He had lost most of his teeth. He was unable to eat by himself.

But I held him. I hugged him. Starting July 12, I spent five or six hours, sometimes more, with him every day. The staff, the nursing staff and the support workers, were there supporting us both. I have to say that these were very difficult times for me.

I'm an active member of the Family Council, and I recognize the sadness and frustration of other families and especially family caregivers. I'm lucky. I can spend time with my spouse every day. Other families are limited to a few visits a week.

Also, I have to get tested. Starting in December, I have to get tested every four days

to show my results every six or seven days. But the staff gets tested only every seven days. So I'm wondering why every four days for me, and Family Council members have the same question. Why us? I mean, we have an important role to play with our loved ones.

My staff lost capacity every day. We had to feed him. He sleeps a lot, almost no longer speaks, has trouble even uttering a sentence.

But he smiles every time I come in every day. His eyes are filled with happiness and love. Every time I visit, he asks me, Are you still there? He cries when I have to leave.

He develops a profound connection with the priest in the villa. In December 2020, we prepare with him for him leaving this world. On January 17, we have a Zoom celebration of life, a healing celebration, and a forgiveness celebration with our three children. What a blessing. What a miracle.

On February 4, he goes into palliative care. I am very grateful because, with my children, I can spend his last few hours with him at the villa, in the home. I spent the next four days with him. I can see the nurses, the

residents, the workers, come in to say good-bye. On February 7th, he left us where he will find eternal peace with God. I am very grateful for having been able to walk with my husband despite the very difficult situations with COVID-19. Thank you.

DAWN PALIN ROKOSH: Thank you very much, Participant 2. I am so, so sorry to hear about your experience. I am so sorry for your loss as well.

Thank you for sharing all that with us. Thank you.

Okay. So now I am going to call on Participant 3 to share your experience with the Commission. Participant 3, would you like me to re-read the question?

PARTICIPANT 3: No, I am okay.

DAWN PALIN ROKOSH: Okay. Thank you. Over to you.

PARTICIPANT 3: Well, thank you for allowing me to have this opportunity. I share many of the comments that the other participants have shared probably throughout your whole Commission.

I too have a mother who is in long-term care in a secure unit. The anguish of not being

able to go in to see my mother over the time of wave one was just -- I can't even explain until you have gone through it.

The only good thing for me was my mom was on the main floor, so I could do a window visit, and I could also see the members of her community in her unit to understand where -- the pulse, because you could see, although our home had done such a great job of the infection control, we have had some outbreaks. We haven't had the devastation others have. We have lost people. We did have outbreaks. But I was able to see how they were doing.

Outside of the infection, you could see the deterioration of people with lack of stimulation, without lack of touching, without enough Life Enrichment people to keep the mental health of the residents together. It was just alarming how quickly we could see the deterioration, not to mention those families who could not see their family members. I was lucky. I could see.

And as a dementia -- my mom has Alzheimer's. She doesn't do well with FaceTime. She doesn't understand it. We can't have those

communications.

Through many of the stories we have heard, we know we have lack of staffing. We have lack of Life Enrichment staff, which I think is key. And we have four Life Enrichment people within our home of 280 residents, not enough prior to the pandemic or through a pandemic.

But what I wanted to bring to you today is a bit of a story that is not good from prior to a pandemic and even worse during a pandemic.

My mom has been in long-term care for four years, was brought in to the secure unit, and as -- this is her residence. This is her family. This is where she has been for four years.

As family members were allowed to come back into the home, and we were able to bring them out into the sunshine, start building back that love and that they know we were there. In the August -- yeah, August time frame, the home came to me and said, You know, we need to move your mom out of the secure unit. She is not exit-seeking any longer, and she is not -- she is very compliant.

Shocked, really shocked. This was a good news story prior. My mom is doing well, given the circumstances, in a secure unit. My mom has

never been an exit-seeking person prior to going into the home, but was given secure unit before. I had many conversations with the home saying, This is not going to work. When you move her out, she is going to start exhibiting lots of issues. She was compliant -- when she moved from her home into -- our family home into long-term care, it was a very hard transition, and we had to move her back into the secure unit because they have more staff. Not enough staff, but more staff. The ratio is three PSWs to 17 residents, as opposed to in all the other units, two PSWs to a unit.

Life Enrichment, we had a dedicated Life Enrichment person to the 16. In the other unit, it is one over 64 residents.

After lots of discussion trying to understand -- so the unit had an empty bed already and an empty ward bed. Their premise for moving my mom was they needed the room. There was somebody on another floor that they needed to get into the secure unit.

My challenge to that was you have two other rooms. You also -- their view was exit-seeking, which my mom was not exit-seeking, but there were many in wheelchairs and actually

some that were bedridden that could have moved. I mean, none of us want to be moved into locked-in or out, but my mom was doing well in locked-in.

I went to the MPP. I couldn't get through. They were not listening. They tried to say my mom would be fine, don't worry, we'll put lots of extra care. The transition, if it doesn't work, we'll move her back. I said, Well, what happens if there is no beds?

I, after many meetings, decided to go to my MPP and go to the Ministry of Long-Term Care and did not get any support in that. I mean, they listened.

The Ministry of Long-Term Care, my question was very much, What is the criteria for a secure unit? How is the decisions being made of who needs to move? And quite frankly, these are people -- whether you are in the secure unit or not, this is their home. They have been there for many years. You are going to rip them out. We are in a pandemic. We have already seen decline and now we are going through this again.

The MLTC very much -- and I think it is very much in the bank. If you set your procedure, they'll come audit the procedure. There is not

enough is the procedure right. The long-term care homes have the right to create their procedure, and the audit is more about did they do what was on their piece of paper. Nowhere could I find any ramification or anything that pointed out why my mom was chosen, and I asked the Ministry to say, Can you just make sure the criteria made sense? Even though I don't think people should be moved. This is their home.

I didn't get anything. So move to October, right before Thanksgiving. The move was happening. My parents 58th wedding anniversary. I couldn't get them to delay it after the Thanksgiving weekend, because the Thanksgiving weekend, if you remember, really was the first holiday we had had to bring our loved ones out and celebrate a time together. We hadn't seen them since April, and now we are seeing them. It didn't happen.

So we moved my mom. I had said to them, This isn't going to be good. So we moved. The first couple of days, threw up, very sick, put in isolation, fear of COVID. I mean, we understood that, kind of not happy.

But the decline started. Three weeks

of my mom. My mom lost 13 pounds. Now she is not in isolation at this point. We did a couple of days. I'm having to go in every day. She is not responsive. She is not communicating. She is not eating. She is not knowing how to eat. We had to get a speech pathologist in.

The PSWs on that floor are not understanding dementia and not being able to approach, being combative. Like they are trying. They are not physically combative. But they don't know how to get my mom to do things. She's left in her bed half-changed while people come around the room. I have a camera in there - just so you know -- now coming around and not recognizing there is a person there. Degrading.

No activities happening, not enough happening. Now we got COVID on the floor. My mom gets COVID -- well, actually, let me wind back. Before that, I have another meeting three weeks after saying to the home, This isn't working. My mom isn't even talking. She has lost 12 pounds. She is not doing -- we need to move her back.

And her room is still empty three weeks later. Can't talk to me about why the room is empty, it is a privacy issue, will not move my mom

back, told me they never said that would happen, could not get her back.

They put some other things in place. Not good enough. I spend lots of my time getting her back, feeding her, helping.

Now there is people there that are very good, but there is not enough people, and we are in isolation. And as I said, then we hit COVID. Luckily my mom had a mild case of COVID. We had nine people. Unfortunately we lost four. My mom got through.

It has been a struggle working through this with my mom. It was a struggle prior to this move. And the fact that they can move people is just not right.

I am now February. I will say my mom has come back a bit, but that is more from the time and effort I have been doing and pushing to get BSOs in, to get more activities happening, and sometimes I feel guilty because my push is taking away from somebody else, and I am on the Family Council too, so advocating for all of our family members.

It is just -- it has been a horrible ordeal. She is getting better now. Her room is

still empty, the one on the secure wing. There is still three rooms empty on that floor. So I still do not know why this has happened and how in these circumstances this could happen. Even prior to a pandemic, I would say it shouldn't happen. Legislation needs to change that says these are people's homes. None of us would like to be ripped out of our homes. She had no community any longer.

In a meeting after COVID, as well my mom had COVID, the discussion, me trying to advocate, they said, You know, you have to understand this floor cannot do what the floor your mom had, and I said, Forgive me, but it was your decision to move her from a floor that to me was still under but was better than any other floor. That was your decision, and now you are telling me you can't cope. I had a nurse say, I don't understand why she is here. We don't have the activities to help her.

So that is my story, along with all the other pieces that other family members are going to go, they are all the other pieces around, you know, staffing, et cetera, but this I think was a point that I wanted to kind of share because it was a little different but it was still part of COVID and

exacerbated the ordeal even more.

DAWN PALIN ROKOSH: Thank you, Participant 3, for sharing that, and for sharing your experience. I am sorry it has been such a struggle. And we'll look forward actually to hearing some of your insights into some of the recommendations under question 2 for things that would improve the situation going forward.

So thank you very much for sharing that.

PARTICIPANT 3: Thank you.

DAWN PALIN ROKOSH: I would like to now call on Participant 4 to share your experiences with the Commission.

PARTICIPANT 4: Thank you. I appreciate this opportunity.

So my mother has been in a for-profit long-term care home since June 2018, so two and a half years now. She has vascular dementia and was doing relatively well, walking safely throughout her unit all day as her activity, eating well, able to sit at programming and to enjoy. We called her confused but happy go lucky.

I visited her monthly from where I live in the United States, and my brother, who lives in

the area, visited weekly.

Our concerns at that time, before COVID, were about some poor management and follow-up of medical concerns. In retrospect, our concerns are critical issues in the home's ability to manage during the pandemic. So I would just like to mention them in a little bit more detail.

Follow-up of medical concerns like urine samples getting lost or not getting to the lab, weight measurements not being accurate, reporting to us about concerns not being sufficient, not identifying issues and being proactive with us, the family, and a lack of connection with the doctor on the team who did not attend care conferences.

Additionally, the home is staffed by a person who does not have a medical background, the Manager -- the Executive Director, I guess, and a relatively low profile and low activity from what were called Co-Directors of Care, one of whom was moved to another home at the end of the outbreak and unavailable to work with families afterward.

Again, in retrospect, these concerns are pretty significant given that they had to go through a pandemic with those issues.

My mother got COVID last spring and survived at this home that had over 70 cases. That is almost 75 percent of the residents. Her dementia has progressed further and faster than expected due to that trauma and over the period of time, and this woman, who walked 10 hours a day, is now using a wheelchair with no step-down from full walking. She is not bearing weight at all anymore.

The bottom line is that dealing with my mom during the pandemic and the results of dealing with her is that we saved our mother's life, and she likely would have died from neglect. She lost over 20 pounds in a matter of weeks and was nearing death by starvation because we were locked out and unable to help her while staff were off recovering from COVID.

As part of her care plan, we receive an evening call every night from her room. The staff call my number, and I direct the call to my brother or my niece or myself, and we answer and stay on the phone with her, and she usually falls asleep during that call.

While she was sick with COVID, we noticed that she had no energy at all and that was very alarming, and that is what got the ball

rolling in saving her life.

The home did not appear to notice it. The home did not report it to us. And we went into action when we noticed that. My brother showed up at the home at a time when we were considered unable -- or we were -- no families were allowed in the home at the time, and he showed up and said, "I am coming in to see my mother." And they wanted to prevent him from doing so, but in conversations at the door, he prevailed, and they let him in.

We then realized that she couldn't eat because she had absolutely no strength, that she could drink, that she could still swallow, that she could eat soft foods if given to her, but she needed an hour to an hour and a half to be fed.

So we alerted the staff to this. I am sorry I'm saying that. I'm incredulous that I am saying that. We alerted the staff? That they did not recognize it or notice it or respond to it. We got the nutritionist involved, and it was such a simple fix. The nutritionist, upon noticing this, said, We can make her eating easier by providing her completely pureed foods.

Once she got on the pureed diet and someone paid attention to her and sat with her for

an hour per meal, she ate all her meals and her strength came back just a hundred percent, just unbelievably incredibly.

She did definitely almost die. And they actually, once letting my brother into the home, said, Well, we have let you in because she is palliative, but she had not been diagnosed -- she had not been recorded as palliative until we brought this to their attention.

We also found that the home during COVID created barriers to essential caregivers visiting their family members, and this is very important. Sometime before or perhaps slightly after COVID started, I reinstated the Family Council and got people talking to each other. And the home's barriers included locking out -- preventing essential caregivers from visiting if they lived in a gray area of the province, then preventing essential caregivers from visiting if they lived 20 kilometres from the home, and then preventing essential caregivers from visiting at all.

These were barriers created by the home without any direction from Public Health or the Ministry.

When they were having meetings, there was obviously no clear plan or understanding of how to manage this. Outdoor meetings held in shaded areas were frequently cancelled due to heat or humidity during the summer. Limited venues for outdoor visits were available so that only one could take place when there were four or more entranceways to the building where they could have taken place simultaneously, and limiting visits to once a week, really a poor, poor response.

And then one other item that I think we are very concerned about is something that I believe folks will need to look into and fact-check. There have been reports to the Ministry, some of which have been replied to and some which have been replied to either poorly or not at all and responses not replied to, but my brother repeatedly reported strong, foul fecal odours in the hallways up to 18 months prior to the pandemic. Staff carried soiled clothing and bed sheets from residents' rooms and placed them into fabric laundry carts stored in the hallways. The odours coming from the laundry carts were excessive as a result of those housekeeping procedures, and they were totally preventable.

We recommended bagging the items before removing them from the resident's room, but that idea was rejected.

The ventilation system, which was no more than five years new, could not exhaust the odours in a timely manner. Warnings of fecal-oral transmission were issued early on when the pandemic hit, and we know that sewer samples conducted for the City of Ottawa showed heightened levels of COVID-19 even before nasal testing results reported coinciding increases.

Long-term facilities have a much higher than average incontinence issue, and staff encounter fecal odours on a regular basis. Fecal odours could have been solely responsible for widespread outbreaks of COVID-19 in long-term care facilities when inhaled by staff and then passed on to other patients. Even new ventilation systems that meet building code today may not prevent the airborne viruses from spreading is our understanding.

New ventilation standards to address airborne viruses should be developed and mandated, especially in these kinds of cases.

So our question is, how in the future

are we going to keep residents, staff, essential caregivers, and other visitors safe from airborne viruses that can be spread through fecal-oral transmission routes, and certainly, you know, where is the Ministry, Public Health, and the home in ensuring that monitoring of these homes is sufficient and that preparation for pandemics or other emergency issues arise.

Just one other thing about my mother's walking. When she recovered from COVID, she stood up and walked out of her room. She was able to walk after COVID. We requested assistance for her to get more attention. We knew that she would need some type of physiotherapy because her walking was a little stilted, and at some point, the staff got concerned and started to walk with her because they were afraid she would fall.

They declined to offer us any additional physiotherapy or assistance in additional walking, even though there were a couple of other residents on the unit who got 24/7 coverage when awake and staff walked with them all day long. We asked several times why our mother didn't get that kind of attention, and they were unable to answer us clearly. It was my impression

that they were avoiding, you know, dealing with privacy issues for the others, which I certainly understand, but it appeared to me that because my mother was not a danger to herself or others, she would not get that kind of supervision.

And then following COVID, when she needed that kind of supervision and likely would be walking now had she had that kind of supervision, they told us they were doing everything they could but could not offer any more.

You may have noticed in my first sentence that I noted this was a for-profit home. The Ministry must do something about these for-profit homes. They are failing our families, and they failed my mother.

DAWN PALIN ROKOSH: Participant 4, thank you so much for sharing that story of the struggle that your mom and your family have faced over the course of the pandemic, and it sounds like even beyond that.

And we'll look forward to hearing some of your insights into some more -- you have addressed some of them in your comments here, but any other insights you have about ways of improving this going forward.

Thank you so much for sharing that.

Participant 5, I would like to call on you, please, to share your experience in caring for a loved one.

Over to you.

PARTICIPANT 5: Thank you for the opportunity to be able to talk to you about what happened.

Hello. It is in May 2016 that my mother was admitted to a residence of 160 beds that fell under municipal responsibility. She was 89 years old.

Her adaptation to going from a certain autonomy, independence, that she had when she was living alone at home was very difficult because she became completely dependent in a residence. They didn't have any choice of becoming completely dependent because there is nothing in the room. There is nothing for her to do. There is very little.

And then it was in 2019 that my mother lost the use of her legs, and she became a prisoner of her wheelchair, and also she had to be transferred by the PSW. That was very difficult. And to this day, she is very concerned when she

needs to be transferred for bathing, but she still was able to take advantage of her 10 children and her grandchildren and other people who were visiting residents because she knows the vast majority of the people in her community.

In 2020, COVID-19 was another very difficult experience because her condition, which was basically of light dementia, really got worse. The grief this caused in my view is the fact that she was alone. She was alone most of the time in her room in front of her TV.

The inside of the residence became silent. Residents could no longer go from one area to another. There were no longer any visitors, and my mother was resigned to simply wait beside her phone in case one of her children would call her. And there was the TV that was always showing news from Quebec and Ontario, and the news was presented that it was a serious and imminent danger and COVID-19 every second sentence.

When I would call her either by phone or by Skype, for many weeks she would say, Something is happening, something is happening. And she would often repeat that sentence. I would explain to her, Yes, it is serious. There is a

virus, a bit like the Spanish flu.

And I realized that she didn't understand the extent of the pandemic and -- because her concern was simply too great.

Social activities were cancelled, so there was no personalized stimulation except with Skype. I really felt her fear of the unknown and fear as well of people with masks. My explanations as to why we could no longer visit, that just increased her confusion when I was trying to explain to her the strict measures to avoid the transmission. So her socializations was basically going to take three meals for 30 minutes at two metres from other residents in complete silence.

And she would then at some time be able twice a week -- sorry, to be able to call one of the personal support workers for help to be able to go to the bathroom. This was very frustrating because it is not pleasant to have to wait a long time when somebody has to go to the bathroom.

Once that she was transferred on to the toilet, she has to ring the bell again, and then wait again until two P SWs arrive to be able to transfer her back to her room.

The quantity of tasks for each of the

residents is so long that the PSWs don't have a minute to lose, and they cannot allow themselves to wait. There are a lot of other residents who need to be transferred. These are tasks that many of the residents would like to have done at the same time.

But when she talks about her life in the residence, she says, Well, you know what? I spend my life on the toilet. Certain PSWs are quite good with being warm, but others don't have a lot of this warmth. Many of them speak French, which aided the comprehension, depending on the verbal capacities of the residents.

But many PSWs can't even say "bonjour". When I see this lack of human warmth of conversation in English to a Francophone, well, I just think residents are being treated like mannequins. All the tasks have to be executed impeccably at an incredible speed. Probably respecting the case mix index, so there is staff missing. When there is staff missing during a period of time, the residents are treated like a mannequin. They are either in a bed or in a chair.

What happens when there is a beginning of symptoms? People don't see it. A few seconds

to better understand what is happening? No, there are no extra seconds to give help.

To what extent do the PSWs are able to see when there are new symptoms? They just don't have enough time. It is not okay to treat our friends or our elderly people as mannequins in another language. The expectations of the populations on the PSWs' work with respect to the residents are obvious. This is very concerning.

During the pandemic, there is an annual meeting to review the plan of care, and this meeting was cancelled. Obviously my mother's mental health has fallen a lot, and there was also a cognitive decline. For those who don't know, when a care plan is reviewed, there are many exams that are done to check, for example, on the person's weight, depression, anxiety, even how close these people are to death. There are a number of criteria. I took my file out, if you would like to talk about it.

Even from her weight, we couldn't even compare her weight at the start of the pandemic and her weight today. I have her plan from a year ago. I would like to compare it to today's results. With these data, perhaps we could see how quickly

she declined.

My perception is that is the price to pay for having prevented COVID-19 from breaking out in the home because there were no outbreaks.

In the last year, the children have found it very difficult to talk with her. It is emotionally difficult for her and for her children. She gets angry because she can't say what she wants to say. She works really hard to find the words, but she rarely does. She says there are too many things in her head. It is very sad.

And the word "sad" really can't describe that feeling. I have to say that even I am thinking of suiciding before I'm admitted to a long-term care home. To manage that sadness, I am active within [inaudible] network, and during our Zoom meetings that we have had on a weekly basis, and sometimes we had them every two weeks, we talked about issues having to do with the shortage of PSWs, a lack of visits, the lack of care, and the huge number of beds, agism, et cetera, among other things.

We also shared our thoughts to draft letters to send to the Ministry, a collective letter that represented the Family Council's views.

I felt nonetheless lucky that we didn't have any outbreaks in my mother's home and very worried with the whole organizational situation for all of the homes in Ontario, for all the homes in Canada, and the poor management of some long-term care that we heard about in the media.

For now, that is what I had to say.

DAWN PALIN ROKOSH: I would like to thank you very sincerely, Participant 5, and I am really sorry to hear about your experience. Thank you so much.

So I would like to call on Participant 6, please, to speak to your experience during caring for a family member, a loved one in long-term care during the pandemic.

Hi. Over to you.

PARTICIPANT 6: Hi. Boy, I got off real lightly compared to the other five participants.

My wife has been in -- it is a non-profit, and I would like to make that clear. I think that is a big part of the success that she has had.

So my wife, unlike most of the residents, she had an operation, a brain tumour

removed, and there was complications, and that is why she is in a long-term care place. She has been there since July 2017.

And she had been making a lot of positive progress in terms of getting cognition back and her brain finding new pathways to run her life.

Unfortunately, she is in a wheelchair. She needs to be transferred with a sling to -- between the bed and the wheelchair. She has to wear a diaper. She somehow just can't remember that she has a diaper on. It is astounding. All the things that she has learned to re-remember, that is something that somehow she can't do.

Anyways, with the pandemic, the lack of contact has been a real issue for her, for myself as well. I was visiting her every day. I wasn't able to visit at all for a number of months. Sadly, for whatever reasons, FaceTime wouldn't work on her phone, so I could only talk with her. And communicating with my wife means having a PSW or a nurse come in and answer the phone. She can't manage to do that.

And the staff are almost to a person wonderful. However, you can only do so much.

There would be a lot of times when, instead of having three PSWs on the floor, there was two PSWs on the floor, and these mostly women, but a few men, just running themselves ragged trying to meet the needs of the various residents. I am not sure how many are on the floor. There is about 30 or 40 on the floor.

The lack of social interaction really -- was really damaging to my wife. She would cry about it. You know, she misses being able to touch, being able to smell me. You know, the staff who she mostly knew, it became hard to delineate who is who with the masks, and it was upsetting to her.

One of the -- when things started to ease up -- I am in Toronto. When things started to ease up, people were able to start going to parks, and we were encouraged to go to the park. I asked the administration to have permission to take her. She is right across from a downtown -- a beautiful downtown park. And it took about three weeks. They said, We'll have to ask the Ministry, because as I think we all understand, these LTCs can only do what the province allows them to do.

And so it took about three weeks for

them to say, Okay, but only once a week, and it was a real boon to her. She really started to come out of a bit of a shell just being able to feel the air on her and see other people and stuff and be with me.

But then that stopped in the fall, and it became -- you know, all the gains were, you know, regressing again.

One of my questions is this -- and I asked the administration numbers of times. I live by myself. I keep myself safe. I get tested once a week. These are all things that the staff in the home do. Why can't I come in and help her with her -- especially with her eating? Eating is something that is absolutely crucial to her life. Three meals a day, she lives for them. It is difficult for her to use a spoon or a fork. She can start off that way, but it is just too -- it takes too much concentration, and she is hungry. So she reverts to eating with her hands -- with her hand, and then she has to wait for somebody to be available to clean her hand off.

These are such small things compared to some of the other stories, I'm almost embarrassed, but at the same time, it comes from the same

source, a lack of personnel. There is just not enough money in the kitty to hire enough people, and there is not enough money in the kitty to pay them not to come to work when they are sick. And I don't see any change in that respect from the province, and not just with nursing homes, with long-term care places, with all sorts of essential workers who are not being given sick leave to be home sick instead of spreading their -- whatever the disease is.

The Life Enrichment, which for my wife is so very important, she gets three hours a day. That is the provincial -- that is what the province calls for, and that is, in her case, four times a week. It is just so pathetic, so pathetically short of a person's needs.

I have become an essential caregiver for I guess now six weeks, which means I have jumped the line. I got my second vaccine yesterday, and I am grateful for that.

I am only allowed to see her twice a week, and they bring her down to the lobby because it is a shared room that she is in. I don't understand the reason for this because I look after myself the same as everybody else who works there,

and in another four weeks, I believe, I will reach maximum efficacy, and I am going to want to know why I cannot be in that room with her.

So far, I have had zero answers from the province on any of my questions, which involved, you know, visitation and now with -- involved with visitation. I find the province just, I don't know, close-mouthed. It seems like they have got to wait to speak with business people before they can make any decision about the health care in long-term care places.

So I feel -- I didn't hear too much anger. I feel very angry with the province. They started off -- Doug Ford started off seeming like he was doing a really good job, but after that first lockdown, money is the thing that is calling the shots.

And my heart goes out to the other five participants, the grief you have had. I have the wonderful future of my wife does get better. It is not the same as Alzheimer's.

So I thank you for the time that you have allowed me to talk.

DAWN PALIN ROKOSH: Participant 6, thank you so much for sharing your experience, and

I have to say it has been very valuable.

So thank you very much. And I'm sorry for the challenges that you have been facing in trying to see and visit with your spouse, but I thank you very much for sharing it. It has been very helpful.

And thanks to all of the participants who have spoken to share their experience, many difficult experiences that you have been sharing with the Commission.

We are going to move now to -- I am going to hand things over to my co-facilitator, Alain Daoust, and he is going to lead us through your responses to question 2.

So over to you, Alain.

ALAIN DAOUST: Thank you very much, Dawn, and just since Participant 1 has answered both questions from the get-go, I will proceed right now directly with Participant 2 for the question.

So for the second question, Participant 2, reflecting on your experience, is there anything that could have been done that would have made the situation better, and what is the most important thing that the Commissioners need to know as they

consider recommendations?

PARTICIPANT 2: What I would like, actually, listening to the other five presenters, I understand what you went through because there is feelings that I have done too.

So let me get back to French. I would like to suggest recommendations to the Commission.

First of all, I would recommend to implement a provincial strategy, Francophone provincial strategy, to promote and value jobs having to do with long-term care.

We have to give more value to that profession.

My spouse was in a residence designated under French services legislation. There is a huge shortage of Francophone employees in our long-term care homes. The only thing I could see is there was a tag on the door of his room that said "I speak French", but because of a lack of French-speaking staff, no one could speak to him in French. And it is important for a Francophone to be able to be addressed in his or her mother tongue.

So I would really recommend that we work with high schools, universities, and colleges

to encourage people to go into that profession and to give it more value. That is very important.

I think it is important as well to recognize that natural caregivers, essential natural caregivers, as mentioned by other participants, should be on-boarded, and we need to recognize their role a bit more. It should be the case of the nurses and other staff.

Also when there is a wage increase, we need to be fair throughout all the staff working in a long-term home because there are questions then on the importance of each person's role when wage increases are given out or benefits, and I found there were problems among the staff of some homes because of that.

I think the Commission should develop a sub-level of workers. I know that some people are hiring now resident service attendants, RSOs. It is important that each residence, each home, can have a regular contact with someone who will listen to him, will do activities with him. We have to encourage residents in their development, physical development, but also social, emotional, and spiritual. We need to spend quality time with them. We need to encourage them to tell their

story, talk about their life, so that they continue to grow and develop in that crucial period that they are in.

The third recommendation, I would recommend that the Commission should implement a true partnership between the residents, the staff, and the Family Councils. It was mentioned by other people who testified today. Family is a partner in residents' care. Too often, family and Family Councils are seen as a threat for the administration or a hindrance, but the nursing staff considers the family, the essential caregiver, as an asset, as a partner. Family Councils offer presence to residents, motivation, love, which is so, so crucial to help residents.

And families and essential natural caregivers can recommend solutions and strategies to provide for the well-being of the residents.

I can also talk to you about testing, the rapid testing and the antigen testing. I won't speak too long, but why not the same standards for employees and for families or natural caregivers? I had to be tested every four days, to get my results on the seventh day, as an essential caregiver. Why can the employee only be tested

once a week and doesn't have to go through the rest?

Another point I would like to make is that we recommend to the government or the Minister to increase the number of beds for long-term care, Francophone beds. What is a big problem is the communication that comes from the government towards families who want information on Francophone beds in our long-term homes. Very often, the family is bypassed and is given all kinds of information, but not the correct information with regard to having a bed in a long-term care home for a Francophone resident.

I think that family is really the voice of the resident, and we have to respect the family, be honest and clear and specific, to help families help the resident.

Thank you very much for taking those recommendations under consideration. I hope that the Commission will really focus on the needs of Francophone families and the families in Ontario, because long-term care homes have urgent needs in being reformed, changed, so that we can respect our residents, the families, and the workers in long-term homes.

Thank you.

ALAIN DAOUST: Thank you very much, Participant 2. Thank you for your observations. Thank you for your recommendations. We do appreciate them very much.

I will proceed now with Participant 3 to answer the second question, and I'll read it in English.

So reflecting on your experience, is there anything that could have been done that would have made the situation better and what is the most important thing that the Commissioners need to know as they consider recommendations?

PARTICIPANT 3: Thank you. I certainly want to first, Participant 2, definitely from a Family Council and families being at the table, that is imperative.

We know the families. We have the experience. And we are able to sit as partners at that table, and we should be, in all parts of that. So I agree wholeheartedly to Participant 2.

And just one other point. Communication. Participant 6, it frustrates me the most is that you have been told that you are not allowed in. As an essential caregiver, you are

allowed in.

So to the Commissioners, it is a communication issue here. Homes should not be allowed to not let them in. You have been able to be allowed to be in since May or June, so it breaks my heart when I hear that, and it shows communication down the paths and for homes who are either disregarding what the government is saying or not understanding the rules, so that is a big communication issue.

I think for my first, for what I brought to -- I mean, I think what really needs to happen is legislation around residents. No eviction policies allowed. We have eviction policies for all of our -- all of us in this home. Through a pandemic, we are not allowed to be evicted. My mom was evicted from her home. That needs to change and that needs to go. The rights have to be amended to be allowed to protect their homes.

Some other components I would recommend, and it is really -- we have talked about hiring. Hiring needs to happen. Family members need to be participating in some of that hiring. We need to have more Life Enrichment, and whether

it is called Life Enrichment, whether it is called behavioural specialists, we need more activities happening in that home.

A person only gets, if they are lucky, one activity of 15 minutes in the morning and one activity of 15 minutes in the afternoon. They are woken up at 8:30 in the morning, and they don't go to bed until 8:00 p.m. or later. They just sit. There is no activities happening. That has to change. This is not an institution to go to die. This is for people to have activities and a way of life within the home. It needs to change in that sense.

I think for sure from a hiring and wages needs to be looked at, but I think more importantly as well is there is so much waste within the homes. There is so much lack of technology. There is so much lack of business process in there, and I think that really needs to be looked at. People don't know how to turn on TVs. People don't know how to do different things. We can make these homes a lot better and more efficient for -- even if there is two people, there is still more that can be done. We need to hire a lot more people, but I think also technology needs

to start being played and looked at within the homes both from, as I said, all the paperwork nurses have to do. That will alleviate some of this time.

Training. We need to get training into these places, but also through the pandemic, what I noticed was the deployment of staff. Life Enrichment people were portering people and taking time away from their job of giving activities and helping the residents go through and have an active life. Instead, they are portering or FaceTiming. Very high paid -- "high paid", I put quotes, high paid role for portering. I think some of those things need to be looked at from a pandemic perspective and ongoing. Are we doing the right things? Do we have the right structure?

And one other thing I would say is, from a pandemic right now, family members are being tested the most, both from -- I have been tested twice a week since May -- once a week since May, and twice a week, and I am about to go daily with the rapid testing.

We are more protected than the staff. Yet we as family members cannot help in the volunteering program. It is time to open that up

in a way that -- we are in the home already. I can stand at the front of -- I had walking clubs in that. We can still be as safe, keep the numbers down, but allow us to help. We have got 30 percent of families being able -- sorry, 30 percent of the work can be done by families right now. We are not opening that up, and we are only being able to stay in the room of the resident or, for some of us, my mom, I'm allowed to walk a bit in the hall. We could help so much right now, and I think that the homes are looking for direction.

I am in a municipal home, which I think is some reason why we have fared better than most, but at the same point, the directors or administrators are too afraid to take on risk, which I understand, but you do need to take on some risk, risk in the sense of weighing the risk. If we look at family members, we are in the homes already. We could be doing some programming right now.

So that is what I would look to from the government and legislative people. And thank you, everybody, and the stories have just been sad but, you know, it is good to hear everybody is doing better.

ALAIN DAOUST: Thank you very much, Participant 3, and thank you very much for sharing your observations with the Commission. It is greatly appreciated. Thank you.

PARTICIPANT 3: Thank you.

ALAIN DAOUST: I will now proceed with Participant 4. Do you want me to repeat the question, or are you okay with --

PARTICIPANT 4: That is okay. I promise to try to focus on that question and not the earlier one.

First of all, I do also want to put my support behind the other participants. I have not heard a thing from them that doesn't matter. I think everybody is bringing up excellent points, and in particular, Participant 3, thank you so much for being so well-prepared for this and putting across that which many of us want to say and which many people who are not here are unable to add to it. I know that you are the voice of many people, so thank you, and I hope the Commission hears that loud and clear.

I want to just go back quickly to what I answered in question 1 and make sure that I have hit the points that I wanted to hit there that

pertain to question 2.

I did talk about their seemingly lack of pandemic and emergency planning, and that is a critical item that is needed -- was needed and is needed going forward.

I want to talk about the lack of understanding about fecal-oral transmission and ventilation systems in homes being up to snuff.

I want to also remember that the monitoring of non-profit homes -- sorry, for-profit homes but also all other homes, it has to be -- you have to have the same expectations for all homes. Our family members must be safe in any home they live in. If there is going to be a for-profit home, then the Ministry has to step up and do more to monitor it and to make sure that they are meeting the needs of the residents first before their profits.

I think those are the main pieces there in going backwards.

In going forwards -- sorry, I'm just checking my notes.

ALAIN DAOUST: It is okay.

PARTICIPANT 4: Okay. So my understanding is that there was an infection

prevention body that was asked to stand by while a new body in Ontario Health focussed on these issues. There was definitely some cost-cutting to Public Health that affected the safety and well-being of our family members, and I think that the Ministry needs to have a look at that. Again, it is more about the best interests of the residents over the budget. That is what our politicians are there for and our ministries are there for, is to keep the constituents -- to keep the people who live there safe.

Again, if someone was paying better attention, I think my mother would have survived better, and that goes back to the monitoring.

And then the post-illness follow-up, just it is quite unbelievable what the families are expected to do to keep their family members safe and healthy. There doesn't seem to be in the homes someone who is looking out for our individual family members.

The staffing -- I did mention this in number 1, but I'll mention it quickly now. The staffing -- the staff are not necessarily experts in the areas that they are placed in. A Director of a home without a health care background and

Co-Directors of Care -- not a Director of Care who knows everything, but Co-Directors of Care who share were not engaging and assisting families appropriately. So I think staffing needs to be monitored better.

Money and liability were permitted to trump commonsense, compassion and care. Families were treated as if they were the cause and source of the spreading of the virus -- Participant 3 focussed on this to some extent -- instead of being welcomed as a full partner in the war against COVID-19. And that is because the plan was not in place, I believe, and it was very short-sighted. They have known for a long time that a pandemic was coming. Toronto had SARS. The Middle East had MERS. Are we going to be prepared for a nuclear disaster? Was Texas prepared for climate change that they are dealing with this week? We are vulnerable in the name of excessive profit and complacency, and the piecemeal approach that the government and long-term care homes implemented made it even worse. To lock family members out made the whole thing worse.

And then I would like to see the Ministry focussed on requiring the homes to amplify

the need to connect families to each other for advocacy. We cannot reach each other easily. People get a general, Oh, go ahead and join the Family Council, but many do not, and we can't -- it is very hard once a family is embroiled in the day-to-day care of their family member in that home to get their attention to join the Family Council. It was an amazing revelation to the few families that we had access to, and to Participant 6 here, I believe, I assume, that the homes were arbitrary in their decisions and were doing illegal things to keep families out.

Our families need to be together. We need to be connected. And people need to be impressed upon not to hesitate to connect. I think it is our Canadian way to sit back and say I trust the people I have put in charge, but buyer beware. We are now consumers in this area, and we need to make a concerted effort to be connected.

And as such, I would like to know if there is a way that we can be connected to each other following this, if there is some way that we are able to share. I would definitely want to meet again with Participant 3 and others and invite them to be in touch with me. And I am quite comfortable

sharing my information through the Commission if you would connect us, please.

ALAIN DAOUST: Okay. Thank you very much, Participant 4, and yes, you may follow up with us on that matter, and we will be gladly obliged.

Thank you very much for your observations as well. It is much appreciated.

And now we will move to Participant number 5. So Participant number 5, would you like me to repeat the question for you? Is that okay?

I think you are still on mute. If you could turn your microphone on, please.

PARTICIPANT 5: So we cannot allow the shortage of PSWs and other health professionals specialized to -- we cannot allow the situation to continue to get worse. The government or the managers have to see this as job creation.

So what was worrying me a lot is that the provincial government would be able to take power, and a few months after it has taken power, they were able to reduce budgets for long-term care homes and to maintain job conditions and salaries that were not competitive for the PSWs.

I would not like this situation to

happen again while I am still alive.

What also worries me is that it is possible for individuals to arrive in a long-term care home and to make a purchase offer and to become an owner of a long-term care home, all with a view to turning a profit. That really worries me that long-term care homes -- or that a company, rather, can hire somebody just to manage a long-term care home. Are we really looking at all of the issues of qualifications, of capacity, and of expertise?

I am also worried that the provincial government would be able to take power and reduce the number of annual inspections in all of the long-term care homes. We have seen what the results of that are. We have to increase these inspections, maybe three or four.

I am concerned that an inspector could demand that our home make changes and that the home could ignore the recommendations without any sanction. We have seen that in the news, in the newspapers, things like that. I don't want to see that again.

I am also concerned that the government has not provided for a ventilation system in

long-term care homes as described in this week's document Proposed Amendments to O.Reg. 79/10, Long-Term Care Homes Act, for Enhancing Cooling Requirements in Long-Term Care Homes.

With global warming and our summers that are becoming hotter and with huge fluctuations, it is worrisome that there is no air conditioning in the rooms of residents, especially -- or at least for the new homes. That was not in the list of recommendations.

And so it would be important to reinstate a review of care plans on an annual basis. What is the basis to decide on what to do with a resident? These reviews are done with the family members and those who hold proxies.

We must know why there are changes in the behaviour, a presence of anxiety, a change in weight, or other such things that physicians perhaps see during their visits but that we may not be aware of. Nothing should be hidden as far as the health of our loved ones is concerned.

I think that to correct the existing problems in long-term care homes in Ontario and elsewhere in Canada, we need to start by changing the Canada Health Act. That would require that we

re-open that Act to provide for the fact that care provided in long-term care homes be provided by the state under the Canada Health Act. That would provide for better uniformity throughout the country on the following points, homes being designated, ongoing care homes for internal beneficiaries, among others.

Also, the level or type of care offered and the way to assess the care, and the way in which the homes that are regulated not -- and that the management not depend on the owner.

Thank you for this opportunity to make my comments, with a view to making constructive comments.

ALAIN DAOUST: Thank you very much for lending or sharing your comments with the Commission.

We will now go to Participant 6 to answer the second question. Do you want me to repeat the question? Okay. So I think you are still on mute.

PARTICIPANT 6: There we go. Thank you.

Gee, I don't know how much I can add. You five people have been very thorough.

I want to underline the business about profit. I just don't see how you can possibly run a beneficial LTC and make a profit, because it is awfully expensive, and the things that the Commission I can tell are going to be forwarding to the province is going to cost the province more money, and the province has to figure out how to pay for it.

My worst fear is that the recommendations of this Commission, like so many other recommendations, are going to fall on deaf ears and are not going to be pushed through, and we are going to find ourselves in the same sad spot when the next disaster comes.

Participant 2, my heart goes out to -- that your husband couldn't be spoken to in his language. It is just -- my heart just goes out. Being a unilingual person -- and I have done some travelling -- it is just so frustrating you don't know what people are saying. To be in the position of your husband and yourself, my heart goes out to you.

Anyways, I hope our voices get heard, and I thank everybody.

ALAIN DAOUST: Thank you. Thank you

very much, Participant 6, and thank you very much for sharing your observations and sharing your thoughts with the Commission and also to the other participants. It is very appreciated.

And so everyone has had the chance to answer both questions, so this concludes this meeting with the Commission. So I would like to thank all and every one of you for having the courage to share these stories because we know this is not an easy thing for you to do because everyone in this room has been through a lot, and we are cognizant of this reality.

So thank you for taking the time to share your stories with the Commission.

And now, if I may, I would like to hand it over to Commissioner Kitts who will be making the closing remarks.

COMMISSIONER JACK KITTS: Merci, Alain.

Thank you all again for the courage in joining us today to share your experiences with us. You know, seeing this tragedy through each of your eyes and listening to your heart-felt messages has been really helpful in making the impact of this pandemic very real for all of us.

We'll do our best to submit a report

that reflects your personal experiences and recommendations to government so they and the general public understand why this tragedy must never happen again.

And I think you summed it up well, Participant 6. You summed up that your voices -- you hope that this meeting today will make your voices heard.

We will do our best to do that. And again, your presence today will help us shape us our report and get the voices heard.

So thank you very much. Merci beaucoup. Thank you.

COMMISSIONER ANGELA COKE: Thank you, everybody.

COMMISSIONER JACK KITTS: Bye-bye.

DAWN PALIN ROKOSH: Thank you all.

ALAIN DAOUST: Thank you.

-- Adjourned at 2:56 p.m.

REPORTER'S CERTIFICATE

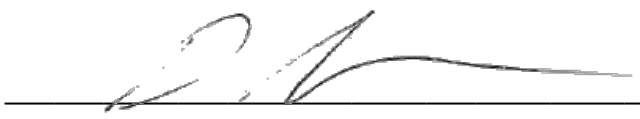
I, DEANA SANTEDICOLA, RPR, CRR, CSR, Certified Shorthand Reporter, certify:

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 19th day of February, 2021.



NEESONS, A VERITEXT COMPANY

PER: DEANA SANTEDICOLA, RPR, CRR, CSR

WORD INDEX