

Legislative  
Assembly  
of Ontario



Assemblée  
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de l'Ontario

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**Official Report  
of Debates  
(Hansard)**

SP-52

**Journal  
des débats  
(Hansard)**

SP-52

**Standing Committee on  
Social Policy**

Improving Dementia Care in  
Ontario Act, 2024

1<sup>st</sup> Session  
43<sup>rd</sup> Parliament

Tuesday 8 October 2024

**Comité permanent de  
la politique sociale**

Loi de 2024 sur l'amélioration  
des soins aux personnes  
atteintes de démence en Ontario

1<sup>re</sup> session  
43<sup>e</sup> législature

Mardi 8 octobre 2024

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Chair: Steve Clark  
Clerk: Lesley Flores

Président : Steve Clark  
Greffière : Lesley Flores

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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

## STANDING COMMITTEE ON SOCIAL POLICY

## COMITÉ PERMANENT DE LA POLITIQUE SOCIALE

Tuesday 8 October 2024

Mardi 8 octobre 2024

*The committee met at 1000 in committee room 2.*

### IMPROVING DEMENTIA CARE IN ONTARIO ACT, 2024 LOI DE 2024 SUR L'AMÉLIORATION DES SOINS AUX PERSONNES ATTEINTES DE DÉMENCE EN ONTARIO

Consideration of the following bill:

Bill 121, An Act to enact the Improving Dementia Care in Ontario Act, 2024 / Projet de loi 121, Loi édictant la Loi de 2024 sur l'amélioration des soins aux personnes atteintes de démence en Ontario.

**The Chair (Mr. Steve Clark):** Good morning, everyone. We're going to call the Standing Committee on Social Policy [*inaudible*] for public hearings on Bill 121, An Act to enact the Improving Dementia Care in Ontario Act, 2024. The Clerk of the Committee has distributed the information to committee members virtually by SharePoint.

To ensure that everyone who speaks is heard and understood, it's important that participants speak slowly, clearly and members of the committee ask their questions through the Chair.

I'm just really excited to have the bill sponsors, the member for Thornhill and the member for Mississauga Centre. So I will call on MPP Laura Smith and Minister Natalia Kusendova-Bashta to begin the public hearing portion today.

You have 20 minutes to make your opening statement, followed by 40 minutes of questions from members of the committee. They're going to be divided into two rounds of seven and a half minutes for the government, two rounds of seven and a half minutes for the official opposition and two rounds of five minutes for the independent member. I will provide reminders of the time with one minute remaining in each round and one minute remaining in your presentation.

I just want to welcome you. The floor is yours.

**Ms. Laura Smith:** Hello, everyone. My name is Laura Smith, member of provincial Parliament for Thornhill. I want to thank the committee members and all attendees for this important public hearing on Bill 121, the Improving Dementia Care in Ontario Act, 2024. I'm honoured to be here today, as this bill represents a critical step forward for families, health care providers and, most importantly, the thousands of Ontarians living with dementia.

Life's challenges can be hard at the best of times, especially when it involves the health of a loved one. But when the issue is Alzheimer's and dementia, the emotional toll is literally so great. Families and caregivers often feel overwhelmed, not knowing where to turn or how to manage the days ahead. Currently, there are over 250,000 Ontarians living with dementia, and this number is expected to rise by 400,000 by the year 2030.

Bill 121 addresses these very challenges by providing a framework for dementia, specifically person-centred dementia care. This bill has one simple but profound goal: to improve the lives of families and patients who are affected by dementia and Alzheimer's. The aim is not simply to treat the disease, but to see the individual behind it, their needs, their experiences and their dignity. By implementing a framework, we will better equip health care providers, care partners and families with the skills and knowledge necessary to offer compassionate, effective care.

While dementia is often associated with aging, it's important to recognize that dementia can happen earlier in life. This is known as early-onset dementia, and it affects many individuals in their forties and fifties, often catching families by surprise. Dementia and Alzheimer's isn't simply something that should be expected to happen as they age. It can be linked to a genetic factor, and in many cases, an early and accurate diagnosis can make all the difference.

Early onset can sometimes be misdiagnosed, leading to delays in treatment that significantly impact the quality of life. These symptoms—such as memory loss, difficulty with words or impaired reasoning—may appear different in younger individuals. This is why raising awareness is so critical. Early detection can improve the outcomes to help families navigate the challenges ahead with greater support.

I'm going to come clean: Not long ago, I was faced with this complex challenge myself—not just once, but twice simultaneously with two very close family members. I know first-hand what it's like to juggle the needs of a loved one with dementia while also attempting to be a wife, caring for my young children and running a business.

Like so many other caregivers, I asked myself every day, "Am I doing enough? How am I going to be in a position to stretch myself far enough to take care of all of these people?" I struggled to get through each moment, wondering, "Will he forget to turn off the stove again? Did

he take his medication?”—or memory pills, as we used to call them. Or “Will she be angry and confused when she wakes up and I’m not there?” Or “How will we he react when a lifelong driver is told that he can no longer drive?” That weighed so heavily on my head, and I want to thank my cousin for being a part of this journey, because I remember the day we took his car keys away.

Through my own experience, I have come to understand that dementia care is not a one-size-fits-all circumstance. We need a complete care network—early diagnosis, access to resources and personalized care—to truly support those living with dementia and their caregivers. That’s why this bill is so crucial: It offers hope and practical support for families who are struggling, just as I did.

This bill, if passed, will bring real, meaningful change. It will improve and promote dementia care across all sectors: hospital, home care, long-term-care homes, hospices and community services. Importantly, it recognizes the unique needs of diverse patient populations, including women, francophone Ontarians and those diagnosed with early-onset Alzheimer’s.

When Minister Kusendova and I began working on this bill, we wanted both awareness and education. This bill has two key components. First, it requires the Minister of Health to develop a provincial framework for improving dementia care. This framework will work in an effort so that person-centered dementia care is a focus in hospitals, long-term-care homes, home care, hospices and community settings. It will also raise awareness of critical support services such as the First Link program offered by the Alzheimer Society of Ontario. This unique program provides families with a network of support, guiding them through the challenges of their dementia journey. It also provides us with the tools to recognize dementia, assists clients to navigate the challenges that come with a diagnosis and provides programming across the province.

Secondly, this bill provides that the Minister of Colleges and Universities will review the personal support worker standard to determine if changes are needed to enhance dementia care training. This review will ensure PSWs receive the specialized education and hands-on experience necessary to manage the unique needs of dementia patients. These efforts will not only improve outcomes for patients, but will also relieve pressure on our hospitals and long-term-care facilities, allowing people, when possible, to live in their own homes throughout their dementia journey.

Throughout our journey of this private member’s bill, we’ve seen so many positive things that have been implemented for those facing dementia and their families. Minister Kusendova-Bashta and I have travelled to so many clinics, conferences, symposiums, hospitals and long-term-care facilities, interviewing and researching projects that work within the dementia realm.

One of the most significant and memorable was our visit to the DREAM program—that stands for Dementia, Resource, Education, Advocacy, Mentorship—initiated by the Alzheimer Society in the Joseph Brant Hospital. It’s

a program that aims to enhance dementia care within hospital settings through specialized support, diversion strategies and community engagement. They do this by embedding dementia specialists within emergency departments. The DREAM program facilitates timely access to resources and supports for individuals living with dementia and their caregivers. Providing these resources and identifying a dementia patient earlier and possibly keeping that person out of the hospital can be a game-changer for families and those facing dementia, while also freeing up hospital beds for other patients with serious health issues.

I’m proud to advise that, through advocacy and determination, there are now over 14 DREAM programs within hospital ERs throughout this province. These patients can be connected to community programs like First Link that allow for safer and better transitions back into their communities. The DREAM program has significantly reduced hospital admissions for dementia patients. I was advised that at the Brant hospital, they had a success rate of a 57% diversion rate, meaning that more than half of the dementia-affected patients were directed away from unnecessary hospital stays to more suitable supports, allowing patients to live with dignity in familiar surroundings.

By fostering a collaboration between health care providers, dementia care experts and community organizations, we can scale innovative programs like DREAM, improving access to dementia care and offering families the support they so desperately need.

I’m so proud to see this bill reach committee today, and even prouder of the journey we have taken together to get here. When it was first crafted in 2023, I had one goal in mind: to start the conversation. I am confident—and I can say this sincerely—that we’ve seen those conversations happen and expand, opening up new horizons for awareness, education and support.

#### 1010

Over the past year and a half, Minister Kusendova and I have hosted several community Destigmatizing Dementia lunch-and-learns, where we brought people together to talk about issues, including the stigma; share resources; and connect with others facing similar challenges. Like the DREAM program, these conversations are already making a difference.

Our government has invested \$4.1 million to expand dementia-related services like the GeriMedRisk program, and we’re providing \$1.25 billion this year alone to hire and retain health care workers in long-term care.

This bill is more than just policy. It’s a lifeline for families and caregivers across Ontario. It’s about making Ontario a place where people living with dementia and their families and their caregivers can feel supported, understood and cared for. This ensures that our health care system is equipped to meet the growing demand for dementia care, while also providing the much-needed support to those on the front lines. It builds on our health care resources, enhances education and training and works to destigmatize dementia.

I want to thank the many partners we’ve had working with us, including the Alzheimer Society, the Ontario

Brain Institute, the MINT Memory Clinic and so many others that have assisted along the way in bringing this bill forward.

I want to thank the committee members for allowing me to share a little bit about my family's dementia journey. Together, we can create a system where every Ontarian living with dementia is treated with dignity and respect. We have to build on our health care resource-based network and work to destigmatize the conversation surrounding dementia.

I will now pass the microphone over to my colleague, Minister Kusendova-Bashta. We look forward to continuing this important conversation.

**Hon. Natalia Kusendova-Bashta:** Thank you so much, MPP Smith. It's truly an honour and pleasure to be here with you, my partner in crime, on this private member's bill, Bill 121, Improving Dementia Care in Ontario Act.

It truly has been a journey over the last two years, when we began our work. The Minister of Health put us together. At the time, I didn't know Laura had a passion for improving the lives of those living with dementia. But when we made the connection, we started working very closely together, and it was a great fit because Laura, as she said, has lived experience being a caregiver for not one, but two people living with dementia, at the same time, being a mom, being a wife—being what I call the “sandwich generation,” which many of us in this room may be experiencing right now, where we have to take care of our aging parents and, at the same time, take care of young children.

With my clinical expertise and my nursing background, I was a very good fit. I would often say to Laura that, in the emergency room, how many times am I taking care of someone living with dementia or someone who is over 100 years old? So it truly impacts the lives of almost everyone. Everyone has a story of either a mom, a dad, a loved one, a sibling or a spouse living with dementia. So I think it is very, very important that we as legislators do everything we can to improve the lives of those living with dementia.

I want to begin with a quote from Mahatma Gandhi: “The true measure of any society can be found in how it treats its most vulnerable members.” Today is an opportunity to foster a meaningful dialogue on how we can build on our government's success in caring for seniors and those living with Alzheimer's disease and related dementias.

As a member of provincial Parliament and a minister, I believe that dementia and how it affects our seniors and their families is one of the most important issues we are facing in Ontario. Like my colleague mentioned, there are 250,000 people living with dementia in Ontario, and that number is expected to increase to 400,000 in just five short years. And I truly believe that that number is actually under-represented, because of the prevalence of stigma. A lot of people do not come forward to get diagnosed, so this is just the number that we know, but I do believe that number is actually much, much higher.

In June of this year, Premier Ford entrusted me with the long-term-care portfolio, which is an honour of a lifetime

and a privilege to take on. Since then, I have travelled across the province, visiting homes and seeing the work that our talented front-line workers, administrators and volunteers put into care for our seniors.

As you know, many long-term-care residents have dementia. The number is between 70% to 75%, so it is very, very significant. It was just incredible to see the programming and services that are offered in homes across Ontario to our residents. It's really inspiring, because almost every home has a unique feature and a unique program. As minister, it gives me the opportunity to see the best practices and then to be able to put forward policies to share those best practices.

Since I started working on this bill, both MPP Smith and I have met with dozens of stakeholders who are allies in our fight to improve dementia care. This past month, I was able to speak at the Nurse Practitioners' Association of Ontario's annual conference to our government's continued investment into hiring more front-line staff for our homes. In addition, I also spoke at the second annual Dementia Day conference held by the Alzheimer Society of Peel, who will be with us today. I applauded the society's First Link program, a resource that our bill touches on and really wants to raise awareness about that helps families navigate the challenges of a dementia diagnosis. The society, along with tens of dozens of stakeholders, have continued to be steadfast supporters of Bill 121; so much so, that today's hearings, as you know, have been oversubscribed. We are very, very fortunate and lucky to have the support of so many stakeholders across our province.

The inspiration for this bill actually came from canvassing my neighbourhood in 2022 and asking constituents, “What is a top issue in your family? What do you care about?” Over and over again at so many doors I've been at, dementia came up. They would tell me how they have a mom, a dad, a spouse, a brother or a sister living with dementia. This was a common theme among so many of my constituents. It's that kind of response that shows how dementia affects communities, not just individuals.

Taking care of a loved one living with dementia can be extremely stressful and produce a lot of anxiety. It's a complex task to care for one, but also, it's not fully understood; therefore, it has a lot of stigma associated with it, and sometimes families are ashamed to come forward and ask for more help. That's why we need to have this conversation, because we need to destigmatize dementia.

For the past two years, MPP Smith and I have travelled across Ontario hosting lunch-and-learns alongside stakeholders such as Alzheimer Society of Ontario, Ontario Brain Institute, Trillium Health Partners and many, many more. Each organization put on a presentation of the fantastic work they're doing to support people with dementia. Each group—you will hear from many of them today—plays a role in ending the stigma. That is why we named our lunch-and-learns Destigmatizing Dementia. Colleagues, if you remember, we held one here at Queen's Park; I can't remember when, but it was this year I believe

we held one at Queen's Park, and we invited all of you to participate.

**Ms. Laura Smith:** In the spring.

**Hon. Natalia Kusendova-Bashta:** In the spring of this year.

If anyone's interested in hosting one in your riding, please do let us know, because it's a wonderful opportunity for stakeholders to come together, some of them for the very first time, to be in the same room, and actually build some partnerships and see what others are doing in this space in their community.

We had a chance to speak in Mississauga, Lindsay, York-Simcoe, Toronto and Thornhill, and each time, we heard about the incredible innovative work that people are doing in this field, as well as hearing from people with lived experience.

Our bill has two parts: It calls on the Minister of Health to develop a framework to support improved access to dementia care and publish a report on the state of dementia care in Ontario. In addition, it calls on the Ministry of Colleges and Universities to review its personal support worker standard to determine if changes should be made, including whether to require training on person-centred dementia care.

Right now, our government, through many ministries—this is a cross-ministry collaboration—is investing into services for people living with dementia. Last year, the Ministry for Seniors and Accessibility invested half a million dollars into the Finding Your Way program held by the Alzheimer Society of Ontario, which provided training and education on dementia. The Ministry of Health invested \$120 million over three years to support a respite and community dementia program, behavioural supports at home and increased access to training and more. Of course, the Ministry of Long-Term Care invested \$46 million over three years to add 200 net new behavioural support unit beds into our long-term-care homes. In fact, this past August I was at the grand opening of a 17-bed BSU unit at the Kipling Acres home with Minister Michael Ford in his riding. Thanks to our government's investments, more Toronto residents with dementia will benefit from this new BSU.

While all these initiatives are superb, our province still needs a structured dementia care framework. With our bill, we are asking the Minister of Health to identify measures to deliver equitable access to dementia care across Ontario. And upon the publication of this report, we wish to see what the level of inequity is that people experience—

**The Chair (Mr. Steve Clark):** Minister, you have about one minute left.

1020

**Hon. Natalia Kusendova-Bashta:** Thank you; I could talk for a lot more—when accessing dementia care in our province. One strategy we are advocating for is to bring awareness to the Alzheimer Society's First Link program which I mentioned earlier. This program is both an in-person and online resource that helps people recognize the

signs of dementia and how to navigate the challenges that come with the diagnosis.

To conclude, Laura and I—MPP Smith and I—are just so thrilled to be here today to hear from so many amazing stakeholders that have been our partners in this journey. We look forward to hearing from you, colleagues, as well on how we can improve this bill and improve dementia care in Ontario. As Minister of Long-Term Care, this is a topic that is very near and dear to my heart. I can tell you that you'll see more work for my ministry on this topic in the very near future. Thank you for your support, colleagues. I look forward to your questions.

**The Chair (Mr. Steve Clark):** Thank you, Minister. Thank you, MPP Smith.

I will now begin with the government with the first round of seven and a half minutes. MPP Pierre.

**Ms. Natalie Pierre:** Thank you, MPP Smith and Minister Kusendova-Bashta, for your remarks: MPP Smith, for sharing your personal journey with your family, and to both of you for your passion and your dedication and professionalism to drive this initiative forward.

I'm not sure, Minister Kusendova, if you wanted to take a few minutes and finish up your remarks. I know you ran out of time there.

**Hon. Natalia Kusendova-Bashta:** Thank you. I just wanted to say that in my work as the member of provincial Parliament the last two years, but especially since I became the Minister of Long-Term Care, I've just had the opportunity to travel across our province. I think I've visited close to 45 homes by now. Every single home has folks living with dementia. It is something that's very prevalent, and you can see it from the very moment you walk into the home.

I think one of the most striking things is that we need to remember the voices of our residents. That's why we have our resident councils. How do we bring forward policies when we know that 70% of folks that it impacts have an actual cognitive impairment? How do we balance knowing that fact with policy decisions that need to be made?

What is very heartwarming to see is that residents who don't have cognitive impairments take it upon themselves to be advocates for those living with dementia. We've seen that come through some of our resident surveys that have come up, that residents themselves, those who don't have cognitive impairment, actually want to learn more about dementia and how they can live with their roommates and how they can help those roommates navigate those situations.

It is our generation's task to take care of our elders. It is a big task. There are a lot of challenges. But I think this conversation is long overdue, and we need to have it. That's why I really look forward to passing this bill, making sure to improve the lives of those living with dementia.

**Ms. Natalie Pierre:** We heard MPP Smith talk about the impact of dementia on health care providers, families and individuals, so thank you so much for talking about the other residents in the long-term-care homes and the



impact that it has on them and their lives in the homes where they live.

My question is really about stigma. Alzheimer's and dementia are often difficult diagnoses to confront, not only for patients but for their families. And the stigma around these conditions can prevent early diagnosis, and prevent or delay critical care. In your experience, how do social stigmas and misunderstandings about Alzheimer's and dementia affect the willingness of patients and their families to actually seek out and get help regarding their medical condition? I'll start with you, MPP Smith.

**Ms. Laura Smith:** That is a very interesting question. I have to preface this by saying I'm not a medical professional. This is something that I simply experienced through a journey of almost a decade and networking with other families. I was the sandwich generation. We talked about the stigma earlier, but I just want to emphasize the fact that when I went through my journey, people didn't talk about dementia. It was kind of the dirty little secret of the neighbourhood. People make assumptions that dementia is something that happens with age, and that is just not necessarily the truth. If you detect it earlier, you can get in there and make all the difference in the world.

One of the things that I noticed was, there is such a stigma that spouses will actually cover for one another, to the point where a husband and wife are not really providing all the full details to the family, and then that eventually slips into a situation where family members are not aware of the full impact of what's happening to those individuals. Because the families are facing that level of stigma, they don't want to talk about it.

Isolation also adds to that. When you're isolated, you don't have an experience with other individuals and those people don't talk about their issues as much as they would, so people don't understand the complexities that happen behind it.

One of the things that I did not know about when I was going through my journey was First Link. It made all the difference in the world for me, because networking with other organizations to get that conversation going can make the difference. When I was part of an organization or a group where my mother was living, having that group of individuals to talk to, to get over that stigma, made all the difference in the world. You could talk about different possibilities.

I'll give you an example: My mother loved to garden, and providing an environment where we could bring the plants to her and she could actually start working on planting—we could calm her down and we could do things that would make her in an element of ease and happiness, which would make my life a lot easier so I could get back to my children and my family and then juggle everything accordingly.

I want to say that this is something that has now become more prevalent, rather, talking about dementia, and we've noticed that, just in the short amount of time that we've been doing this.

**The Chair (Mr. Steve Clark):** You've got about a minute left in this round.

**Ms. Laura Smith:** Okay. This wasn't discussed at the beginning of the conversation, but it is definitely a part of our conversation right now.

I didn't know if you wanted to add to that.

**Hon. Natalia Kusendova-Bashta:** I would just add that it helps when, for example, public figures talk about their challenges. One very known example is Lisa Raitt and her husband, who had early-onset dementia. I think sharing stories like that really helps other families come forward, and I think that's why it's so important that we're having the conversation today. MPP Smith, sharing your life journey and your life story I think will inspire others to come forward and seek help when the help is needed.

**The Chair (Mr. Steve Clark):** We'll move to the first seven-and-a-half-minute round for the official opposition. MPP Andrew.

**MPP Jill Andrew:** Good morning, everyone. Thank you, MPP Smith and Minister Kusendova-Bashta for your remarks on Bill 121, An Act to enact the Improving Dementia Care in Ontario Act, 2024.

I'm going to speak to the purple elephant in the room that was not addressed in your speech—in either of your speeches—and that's with regard to PSWs and caregivers, and, to be specific, the pay of PSWs. I want to ask a blunt question: Do you believe that your government has respected, protected and paid our nurses, our PSWs, our front-line health care workers the way they deserve?

**Hon. Natalia Kusendova-Bashta:** I'm happy to take that question. As you know, we have made changes to the minimum wage that PSWs are being paid in long-term care. We have raised it from \$15 to \$18. We've done that in the pandemic to ensure—

**MPP Jill Andrew:** I'm going to interrupt you, Minister, because as we know, the minimum wage that's necessary here in this province to survive, to really be able to thrive, is way above \$18.

**1030**

I want to step back and say this: I appreciate this bill. As many of you know, my mother has cognitive impairment. She is living with neurosarcoidosis, and it's tough. So I appreciate you highlighting stigma and the physical, mental and emotional stress for folks with Alzheimer's and their families.

But I want to make it clear: This Conservative government has understaffed, undercut and underpaid PSWs and nurses in long-term care, in home care, in our hospitals at every turn. In fact, your government has taken front-line health care workers to court and has appealed the Ontario Superior Court's decision to name your Bill 124 an unconstitutional bill that directly attacked nurses and PSWs. This is ridiculous.

**Ms. Jess Dixon:** Chair, point of order.

**The Chair (Mr. Steve Clark):** MPP Dixon, a point of order.

**Ms. Jess Dixon:** We are exploring the bill and allowing those who presented to provide their evidence about it versus providing evidence ourselves, so I would appreciate if the member could reach a question that they can respond to.

**The Chair (Mr. Steve Clark):** MPP Andrew, can you direct your question to the minister?

**MPP Jill Andrew:** I'd appreciate if MPP Dixon allows me to question the ministers, which is my right.

**The Chair (Mr. Steve Clark):** Again, to all members: Just direct your comments through the Chair.

Go ahead, MPP Andrew.

**MPP Jill Andrew:** As I said, do you believe that this government has respected, protected and paid nurses and PSWs—you are a nurse yourself, Minister Bashta. Do you believe that the Ontario government, your Conservative government, has paid, protected and respected our nurses and front-line health care workers?

At a time when we know that there isn't enough home care in our province, we know that PSWs are being stretched—they're going to eight to 10 clients; they're paying for their own mileage, their parking, their TTC Presto. Are you all, as government members—this is a good start; I give you that. But you guys are the government. You didn't even have to create this bill. The government could have made these changes any time they wanted—six years ago—since you've been in power. Are you all respecting, protecting and paying our nurses and our front-line health care workers?

Before you answer, I'm going to speak to caregivers. My colleague MPP Wayne Gates put forth a piece of legislation asking for a few lousy dollars to pay caregivers, mostly women, who are taking on the full-time emotional labour, unpaid labour, of caring for their loved ones with Alzheimer's, with dementia, with cancer—oh, yes; I forgot: Your government doesn't even cover take-home cancer drugs fully yet. And this government said no to that bill to support caregivers.

So thank you for talking about stigma and the physical and emotional impacts of Alzheimer's—

**Ms. Natalie Pierre:** I'd like to raise a point of order.

**MPP Jill Andrew:** —but if you don't take care of caregivers—

**The Chair (Mr. Steve Clark):** MPP Andrew, there's a point of order.

**Ms. Natalie Pierre:** I believe the committee business today is around Alzheimer's and dementia care. I would suggest that MPP Andrew kindly revise her questions so that they address the committee business that's in front of us.

**The Chair (Mr. Steve Clark):** Thank you, MPP Pierre.

MPP Andrew, you've got two minutes left.

**MPP Jill Andrew:** Wonderful. That's a lot of time.

To people in the audience here today and to those from St. Paul's who are watching, including one of our constituents, Paula, who wrote a book about her husband's case of Alzheimer's and her care: The government is interjecting because I am asking about PSWs and caregivers—

**Hon. Natalia Kusendova-Bashta:** I'd like to answer your question, if you'll allow me.

**MPP Jill Andrew:** Then please answer the question. I will interject again if I don't think the answer is appropriate.

**Hon. Natalia Kusendova-Bashta:** First of all, I wanted to offer my sympathies for your mom. I didn't know that she's living with cognitive impairment.

**MPP Jill Andrew:** Thank you. I've spoken about her many times in the House.

**Hon. Natalia Kusendova-Bashta:** I offer you my sympathies. I know it's not easy to be a caregiver for someone with cognitive impairment.

Our government has made historic investments into recruitment, training and hiring more PSWs, nurses, RPNs, nurse practitioners—you name it—into long-term care.

**The Chair (Mr. Steve Clark):** You've got about one minute left, Minister.

**Hon. Natalia Kusendova-Bashta:** This year alone, we're spending \$1.8 billion on staffing and recruitment, which is a \$600-million increase from last year—

**MPP Jill Andrew:** I'm going to interject here, Minister. You all do a great job at throwing out the hundreds and the billions of dollars, but they never reach the front-line worker. It never does.

**Hon. Natalia Kusendova-Bashta:** Yes, we have hired thousands upon thousands more health care workers in long-term care.

**MPP Jill Andrew:** And thousands upon thousands of health care workers are leaving. You keep saying that you're doing better than the last government, but the last government didn't do that well. So it's time to increase the standard. It's time to—

**Hon. Natalia Kusendova-Bashta:** We brought in four hours of direct care per resident per day—

**MPP Jill Andrew:** In 2025. We are in 2024.

**Hon. Natalia Kusendova-Bashta:** We are the first Canadian jurisdiction to do so—

**The Chair (Mr. Steve Clark):** Minister and MPP Andrew, for the purposes of Hansard, you can't keep talking over—

*Interjections.*

**The Chair (Mr. Steve Clark):** MPP Andrew and the minister—again, we're almost out of time, but I just want to remind you: For the purposes of Hansard and for broadcast, talking over each other is not going to get your message across. So again, with respect, put your questions through the Chair as we move forward.

Your time is completed, for the official opposition. We'll now move to the independent member. MPP Clancy, you have five minutes.

**Ms. Aislinn Clancy:** I want to start out with a thank you as well. I know both of you come to this with good intentions, and it sounds like you've done your homework. We've seen bills come forward without robust consultation, and I'm hopeful that that spirit of full consultation will continue after the bill is passed, as I am sure it will.

I'm going to kind of stay in the same lane, but swerve a little bit. We do know that there is underpayment. I've worked with, as a social worker, a lot of single moms, racialized folks, newcomers working as PSWs, and they do have vulnerable, precarious work sometimes, especially in some of the more privatized settings, where they

don't have full-time work and they're working split shifts and they're driving.

So that is a factor that can undermine the success of your bill, the pay that these workers are receiving and the working conditions, and we do hear that. I'm sure you've heard from nurses and from PSWs how they feel burnt out and overwhelmed with the caseloads. We do have an aging population, and I'm sure especially in private care—I know we disagree sometimes on what that looks like, but we know that there can be a lot of pressure and a power imbalance in that environment. So how do you intend to make sure this bill is successful when we have a workforce issue?

**Hon. Natalia Kusendova-Bashta:** We have to work across ministries with our partners at MCU, the Ministry of Health, the Ministry of Long-Term Care and the Ministry for Seniors and Accessibility to put forward recruitment and retention strategies, which we have. I'm so proud of the work my ministry is doing in this regard.

Just to continue about the PSWs: Yes, we raised the minimum wage from \$15 to \$18, but the average PSW pay across our homes is between \$24 and \$26 per hour. So we've done tremendous work. We also, throughout the pandemic, had two PSW challenge funds where we trained, I believe it was, 16,000 PSWs who the government paid full tuition for. More work needs to be done, absolutely, and the reality is, working in long-term care is not for everyone, and sometimes people have to try it and sometimes they decide it's not for them. So we will always see a little bit of a turnover.

But I, as the Minister of Long-Term Care, am committed to raising the quality of care in long-term care, and we talked about it during estimates: to have more training on wound care, to have more training for phlebotomy, to ensure that our nurses are working at the full scope of practice in long-term care. We'll continue working with our partners at MCU. We have a new minister, Minister Nolan Quinn. I'm going to meet with him to ensure that we are training the health care workforce for the future.

Long-term care is part of the continuum of health care in our province, but if one sector is struggling, you see the domino effects across the entire continuum. Last year alone, we had 30,000 nursing students registered at our colleges and universities. That's a historic number, so we'll need to continue—

**Ms. Aislinn Clancy:** I do want to pause. Just so you know, the living wage—so this is not going to Cancún—in Toronto is \$25 and the living wage in my community in Waterloo region is over \$20, more or less. So my ask of you—I think, in order for your bill to be successful, we need to at least get to a living wage. I know, as a social worker in the past, when you give people more jobs, more work and more specialization, they deserve also to have that recognized in their pay and in their working conditions. How do you expect to show these staff groups the respect they deserve for the extra training and specialization they're going to get?

1040

**The Chair (Mr. Steve Clark):** You've got about a minute left, MPP Smith.

**Ms. Laura Smith:** One of the things that I was going to highlight that has not been brought up, and Minister Quinn talked about this earlier: micro-credentials, which provide specialized unit care education for these individuals. That's something that our government provided funding for. When Natalia and I—sorry, Minister Kusendova—talked about—

**Ms. Aislinn Clancy:** Can I interrupt for a second, through the Chair? I'm asking about, once you get the micro-credentials, you should get better pay. So what's the plan there to ensure we respect and regard the extra training that people are getting?

**Ms. Laura Smith:** You know what? I think that this is probably one of the most positive steps that our government has made in over a decade when it comes to dementia initiatives. There is no doubt in my mind that the province will be far better off with this initiative and this bill than it was before.

**Ms. Aislinn Clancy:** I don't disagree. I'm looking at it from the perspective of the PSWs—

**The Chair (Mr. Steve Clark):** Thank you, MPP Clancy and presenters.

We'll now move to the government. MPP Pang.

**Mr. Billy Pang:** Mr. Chair, through you to the minister and MPP Smith: Earlier in your presentation, you mentioned stigma. Also, I want to follow up on the question by MPP Pierre regarding stigma. You talked about how sharing stories is one of the strategies. I believe there are more strategies you can share with us. More strategies can be employed to overcome stigma, encourage earlier diagnosis and foster a more open conversation about dementia so families feel empowered to seek help and the resources they need.

**Ms. Laura Smith:** Thank you so much for the question. I'm going to go back and talk a little bit about early diagnosis and programs like DREAM and First Link, because they allow the families that are experiencing dementia, the care providers that are experiencing dementia, to really have a lifeline.

One of the things that First Link provides, which is supported by our government—it means that you receive one-on-one support and referral to local health care providers and community services, and you meet similar individuals in similar circumstances to exchange experiences. It really helps you plan your future when you have this dementia journey in front of you.

I know, with the projected numbers—250,000 individuals right now; 400,000 by 2030—and by the way, this is possibly going to be three times the amount in 2050. That means 250,000 individuals times three. I know that these measures that we're taking and the action that we're going to be doing with this bill is going to make such a positive influence on the dementia landscape.

It's going to be working with integrative care. It would build on our government's success in enhancing treatment for seniors in early onset, getting them the care earlier as

opposed to later and building a comprehensive system of care that addresses the needs of people living with dementia. This will strengthen and showcase our government's efforts and tackle these challenges, demonstrating how Ontario will benefit with an enhanced care system.

**Mr. Billy Pang:** I pass the questions to my colleague.

**The Chair (Mr. Steve Clark):** MPP Grewal and then MPP Dixon.

**Mr. Hardeep Singh Grewal:** First of all, thank you to the both of you for your passion and hard work bringing this forward. It's very, very evident, the amount of work and research that you guys have done and put into this. It really reflects your personal stories and your work stories as well and bringing it back into the Legislature. I'm very, very thankful and grateful to have colleagues like you that are bringing this in. We're going to be doing some great work together.

I wanted to ask a question—either can answer—regarding personal support workers. PSWs, as you know, play a critical role in care for individuals living with dementia, but many experts have suggested that PSW training needs to be enhanced to meet the growing challenges posed by Alzheimer's and related conditions. Could you discuss how incorporating more in-depth dementia education into PSW training, including courses on communications, de-escalation techniques and advanced dementia care, could improve outcomes for patients?

**Hon. Natalia Kusendova-Bashta:** I'll gladly take that question. In my work as a nurse, I have so many wonderful PSW colleagues, but what I've learned is that some of them don't feel fully prepared for the realities of working especially in long-term care, given the fact that 70% of residents in long-term care have a dementia or Alzheimer's diagnosis. So what our bill is actually asking the Minister of Colleges and Universities to do is to review the personal support worker standard, which is sort of our golden standard for the curricula that PSWs across our colleges are learning. That's the standard that is set out by Ontario. We want to ensure that all colleges have a robust piece of curriculum on dementia and communication techniques, such as gentle persuasive approaches—and there are others—so that PSWs through their training learn about it and they also have experiential learning.

Those words—experiential learning—were very important to include in the bill so that those PSWs that are studying actually have experience working with someone with dementia—hands-on experience. It's one thing to talk about it and learn about it in school, but it's a whole different issue when we actually work with someone living with dementia. That experiential learning component I think may be lacking in some of our curricula currently. That's why I want to ensure that that standard is raised so that, when PSWs graduate, they are fully prepared and equipped to work, for example, in long-term care, where 70% of our residents have dementia. But dementia affects people living at home. Sometimes patients in hospitals have dementia. So this is just a good practice to have when you graduate as a PSW.

PSWs are incredible people. When I speak to so many of them, it's a work of passion. It's a work of the heart that they do. They put so much care into working with our seniors, and I am proud of the incredible investments we have done. We are the first jurisdiction in Canada to improve the direct hours of care per resident per day in long-term care: four hours of direct care per resident per day. We're the very first jurisdiction in Canada to legislate that. And when I speak to PSWs on the floors of homes, this is changing the workload. Whereas, before, PSWs maybe had eight, 10 or 12 people to take care of in a day, today the average in certain homes is about six. So the effect of our legislation and our work is being felt across Ontario. Of course, it takes time to get to those four hours, but we're making huge progress, and I'm extremely, extremely proud of that progress that we're making.

**The Chair (Mr. Steve Clark):** You've got about a minute left in this round.

**Hon. Natalia Kusendova-Bashta:** Go ahead.

**Ms. Laura Smith:** I was just going to chime in, because I was a care provider and I do know what those extra hours do for the patients and the families. But dementia patients have unique needs, and some of them exhibit behavioural problems—aggression, emotional distress, restlessness. I was unfortunate enough to have all kinds of those different dynamics. I can advise that, in one loved one's case, it was a slow and steady progression; with the other, it was a fast and sharp fall. Every one of these dementia patients are individuals, and a holistic, integrative approach designed to maintain the well-being and quality of life for that person with dementia is of the utmost importance, and having that specific training that deals with that unique-needs individual makes all the difference in the world.

**The Chair (Mr. Steve Clark):** Thanks, MPP Smith. This concludes the government's second round.

We'll now move to the official opposition for seven and a half minutes. MPP Vaugeois.

**MPP Lise Vaugeois:** I'm basically in support of the bill, and glad to see a conversation about dementia taking place. But I do have some pretty significant concerns about access to actual care.

I see that the Alzheimer Society made some very specific recommendations—as did Ontario Dementia Care Alliance—and one of those is to equalize wages between hospital and home and community care workers performing equal work. What we know is happening in home care is that they are the lowest paid. They aren't paid for their time. It's not a living wage.

My mother was receiving PSWs after a hospital stay. They often don't come, or they come late. They are not paid for their travel time; the travel time isn't built into anything—the care simply doesn't happen, or the client waits there for four hours, six hours, eight hours, and then the PSW arrives. I don't want to blame the PSWs, because their working conditions are inappropriate and the wage is inappropriate. That's a very clear recommendation from the Alzheimer Society.

1050

My question is, will you lobby for equity amongst the—and I will say more than PSWs, because the same thing is happening with nurses, nurse practitioners. If you work in a nurse practitioner-led clinic, such as the wonderful one in Thunder Bay or the family health teams in Marathon, if a position opens up at the hospital, they get paid \$50,000 more. The teams can't hold on to their people, so we need equity across the board for people performing this work, particularly home care; it's some of the hardest work there is.

Will you lobby to create that equity amongst the pay scales, regardless of where the people are working?

**Hon. Natalia Kusendova-Bashta:** I think it's really important for us to consider the different skills that are required in the different sectors that we're speaking of. Of course, a hospital has higher acuity and higher training that is required to work in the hospital, and higher skills. I think we talked about this in estimates a little bit. I can only speak to long-term care; home care falls under the Ministry of Health. However, when we look at long-term care and the skills that nurses have in long-term care compared to the skills that nurses have in the hospitals, we clearly see that nurses are not working to the full scope of practice in long-term care. So one of the things—

**MPP Lise Vaugeois:** I'm going to interrupt you because I do—you can rank experience level, responsibility level, scope-of-practice level when you're determining those pay scales, but there can still be equity amongst those pay scales.

People want to age at home if they possibly can, and that's been repeated again and again by all sides in the debate on care. But if there's nobody there—for example, I knocked on a door recently in Thunder Bay and the husband can't even get a bath once a week because there are no PSWs. Why are there no PSWs? Because they keep leaving because it's just not worth the money. It's too hard, it's too physically draining, they often are injured in the process of doing the work, and it's thankless. They may care deeply about the people they are working with, but they can't put their lives on the line again and again for poor pay.

So I ask again: Will you lobby for equity? The Alzheimer Society is saying this themselves. Ontario dementia care is saying it themselves. Many, many people in professions in health care are asking for equity across the board.

**Hon. Natalia Kusendova-Bashta:** We have increased the funding to home care by \$2 billion this year. Those are significant investments. Again, we have to look at the skills that are required to work in long-term care, to work in hospitals—

**MPP Lise Vaugeois:** I'm going to interrupt again. So, in other words, you consider home care to be a low-skilled environment. You may want PSWs to get training for dementia, but you're not going to actually acknowledge that in any way in their pay scale or in making their lives livable so that they can give the care that people want and need at home.

**Hon. Natalia Kusendova-Bashta:** We have strengthened home care by \$2 billion in the last budget—

**MPP Lise Vaugeois:** The billion dollars are not getting—

**Hon. Natalia Kusendova-Bashta:** Those are incredible investments.

**MPP Lise Vaugeois:** I'm going to interrupt you again, please. That money is not getting to the front line. Unless the money is getting to the front line, you're just talking big numbers that have no meaning for what's actually happening in people's homes. We know that people are not getting care, and they're not getting the care because the PSWs aren't there, and the PSWs aren't there because the pay isn't there and the working conditions are abominable.

**Hon. Natalia Kusendova-Bashta:** We have introduced many programs to support seniors living at home, including the community paramedicine program, in which community paramedics go into people's homes to support them, to provide point-of-care access, to provide some diagnostics. That is a largely very successful program. We have learned from our partners at AMO, the municipalities that help us deliver those programs, of the success of that program. So we're looking to expand it.

We're proposing different innovative solutions to ensure that seniors living at home, perhaps waiting for a long-term-care bed, are supported, and those are significant investments that we continue to make—

**MPP Lise Vaugeois:** All right. I'm going to stop you there again—

**Interjection:** You could be waiting for seven years.

**MPP Lise Vaugeois:** Right. Yes, you might wait a very long time to get into a home. But, for the most part, nobody wants to go to long-term care if they have another option, or if their families have another option.

So what I would also like to ask: Will you lobby in support of the caregiver tax benefit, so that family members are not penalized and obliged to give up their jobs, if they have them, so that they can actually provide help to provide that care? Yes or no? Will you support that?

**Ms. Laura Smith:** I'm going to say that these are positive steps, and I would argue that a framework is definitely in order to get us to the next level, but I'm going to talk about resources. I'm going to talk about one of the programs that the Alzheimer Society provided, which is the DREAM program—

**MPP Lise Vaugeois:** I'm sorry; I'm going to take my time back.

**The Chair (Mr. Steve Clark):** You've got about a minute left in this round.

**MPP Lise Vaugeois:** Yes, I'd like to take my time back, because I asked for a yes-or-no answer—

**Ms. Laura Smith:** I was about to tell you about—

**MPP Lise Vaugeois:** You were about to tell me about other things.

*Interjections.*

**The Chair (Mr. Steve Clark):** MPP Smith, she's got less than a minute left. Maybe we can get a question back from MPP Vaugeois.

**MPP Lise Vaugeois:** Right. So it was yes or no: Do you support the caregiver tax benefit. Yes or no?

**Ms. Laura Smith:** We are here to talk about Bill 121.

**MPP Lise Vaugeois:** Yes, and we're here to talk about how to actually make it possible for people with dementia to get the care that they need. We know that that is one crucial element of how they get that care. Equalizing wages is another crucial element of how they get their care.

I've been dealing with family health teams in north-western Ontario. Do you know that they have not had base increases in funding for 10 years? They cannot keep staff. The staff, then, goes to the neighbouring hospital the moment there is a position open there—

**The Chair (Mr. Steve Clark):** That concludes the official opposition's second seven-and-a-half-minute round.

MPP Clancy, your final five minutes begin now.

**Ms. Aislinn Clancy:** Thank you very much.

I know that we're being critical here, but we want your bill to be successful. We all want good dementia care, and we want to be sure that all aspects of seniors' care are considered, and home care is a big part of that.

Another concern I have about the success of the bill is folks who don't have a family doctor. We know since your government took office, or—I don't know if it was a year ago. Anyway, the number of folks living without a family doctor has risen from 1.8 million to 2.5 million.

I have MINT Memory Clinic. I went for a tour from them. I admire their work. They showed me what MINT memory care means. They are from our region, Minister Dixon's and my region, and they've created a program that went across the province. My concern is that we want to have early detection. Part of the success of your bill is that we can catch family members early on, and part of that has to do with equipping primary care with the right tools—at least that's what I know MINT Memory Clinic was all about.

Knowing that the number of people without a family doctor is only increasing—and I know you're going to give me money, you're going to give me stats, you're going to talk about new positions. But we know that that's not going to translate for five years, and you've told me how many more people will have dementia next year and the year after that. What can we do right now? I know we've been lobbying for supporting the administrative costs of family doctors, so they can spend more time with patients. We've been talking about recognizing and building more of these teams. In my community, we're trying to get internationally trained doctors mentorship. We know it's happening in the north. We need it in urban centres as well.

What can you do right now? These are solutions you can do right now to improve access to family doctors, which will make your bill successful. Are you open to looking at that as part of the puzzle, in terms of making sure the delivery and the early detection happen?

**Hon. Natalia Kusendova-Bashta:** As you know, we need more family doctors, and that's why we are building

three new medical schools, and two of them will have a focus on—no, allow me to finish.

**Ms. Aislinn Clancy:** I know, that's real, for sure.

**Hon. Natalia Kusendova-Bashta:** They will have a focus on primary care, especially at TMU, which is in Brampton. I don't know the exact percentage, but a large percentage of their students will be primary care physicians. And so—

**Ms. Aislinn Clancy:** I know these things. We talked about those a lot. I guess my question is: I've given you two solutions that can help right now. Do you think those also could be considered in this plan? Because honestly, if we have to wait five years, we know that that number is 2.5 million today. I can only guess that we're looking—

**Hon. Natalia Kusendova-Bashta:** I would just remind you that nurse practitioners are also primary care providers. The 2.5 million or 1.8 million actually is, I believe, lower, because we don't count the patients that are attached to a nurse practitioner as having primary care. That's why the number is probably a little bit lower.

But we know we have to make investments in primary care. This year alone, I think the investment was \$586 million that the Minister of Health has made. But we also need to train more doctors, and that's why we're opening, for the first time in decades, three medical schools. This is not a small thing.

1100

**Ms. Aislinn Clancy:** I am grateful; don't get me wrong. It's a big deal. It's decades in the making. This had to happen. I'm just looking at time. We're staring down the barrel of an aging population, right? You said it yourself: the number of people will increase, the number of people needing needs will increase and the number of people without doctors will increase.

Will you also consider, then, having nurse practitioners covered under OHIP? In my community, they're charging a subscription. It's a privatized, for-profit system because they aren't getting recognized under OHIP. Is that also something that you will consider to make sure that your bill is successful?

**Hon. Natalia Kusendova-Bashta:** I know we're consulting with all stakeholders. As you know, there is arbitration with OMA—

**The Chair (Mr. Steve Clark):** Minister, there's about a minute remaining in this round.

**Hon. Natalia Kusendova-Bashta:** I will give some time to MPP Smith.

**Ms. Laura Smith:** I wanted to say that you talked about efforts that we're making right now, and that is happening right now in the DREAM project. When we started, there was one in Brant. We walked through that facility, and we were absolutely—

**Ms. Aislinn Clancy:** Can I stop you? My question—I appreciate that. I did hear your stories. I appreciate the consultation.

**Ms. Laura Smith:** But that diverts 57% of all dementia patients out of the hospitals and into another setting where they can be comfortable. People in that situation need to

go home with the right facilities and not necessarily walk into a hospital facility.

**Ms. Aislinn Clancy:** For sure. I just gave you three things you could do today that would improve access to primary care right now. Those are the things I'm looking for you to do to make sure your bill is successful.

If people go to walk-in clinics—you and I both know. I've been there with social work. If I have a kid with complex disabilities and I go to a walk-in clinic, that's not fair.

**The Chair (Mr. Steve Clark):** Thanks, MPP Clancy. Thank you so much. Thank you, MPP Smith and Minister Kusendova-Bashta, for your presentation.

ALZHEIMER SOCIETY OF ONTARIO  
ONTARIO LONG TERM CARE  
ASSOCIATION

ALZHEIMER SOCIETY OF YORK REGION

**The Chair (Mr. Steve Clark):** I'm now going to call on the three presenters, two of which are here in person, one online: the Alzheimer Society of Ontario, Adam Morrison; the Ontario Long Term Care Association, Chris Pugh, who will be joining us virtually; as well as the Alzheimer Society of York Region, Kari Quinn-Humphrey. I'll ask that the two bill sponsors make way for our three presenters.

As you're setting up, I just want to remind every presenter that you're going to have seven minutes for your presentation. After we've heard from all of the three presenters, the remaining 39 minutes of the time slot will be questions from members of the committee. Again, similar to the first round with the MPP and the minister, they will be apportioned seven and a half minutes for two rounds for the government members, seven and a half minutes for two rounds for the opposition members and two rounds of four and a half minutes for the independent member.

As you're getting ready, I will ask Mr. Morrison, if you're ready, if you could start by stating your name for Hansard and your title and we can begin. Welcome.

**Mr. Adam Morrison:** Thanks very much, Chair. My name is Adam Morrison, and I'm the senior director of public policy and partnerships for the Alzheimer Society of Ontario. I'm very happy to be here today; thank you for the opportunity. I heard off the top that this hearing was oversubscribed, so I'm happy to make billing.

I wanted to start recognizing the leadership of Minister Kusendova-Bashta and MPP Smith. Thank you very much for your leadership. As one of your colleagues said, it's great to be hearing about and talking about dementia again and having that as a priority for the conversation today.

I'm going to be speaking from the perspective of the Alzheimer Society of Ontario, which is inclusive of our 26 local societies. However, it's even better because you're going to hear from two of my colleagues from local societies today as well.

In short form, the Alzheimer Society of Ontario is very much supportive of Bill 121 and its swift passage. It's very aligned with the work that we do. I think folks have already heard a lot about our programs from the bill co-sponsors, so perhaps I don't need to dwell on that too much. However, I will say, if you would like to know more, we are coming to the Legislature on October 22. I know some of the people in this room have RSVP'd already, and I really hope to see all of you there from 5 p.m. to 7 p.m. in the legislative dining room. That's the only plug I have for our society, I promise.

The Alzheimer Society of Ontario and our local societies have existed for over 40 years as the leading charity supporting people living with dementia and their care partners in Ontario. Last year, we served 84,000 clients, and that number continues to grow year on year.

As I mentioned, we're a federation with 26 local societies covering every community in the province, and we also do have involvement across the continuum of health and social care, supporting with training and education as well direct clinical services in our offices; in primary care, as you've already heard; in hospital; and in a number of other care settings, as well. That's also along the entire dementia journey, from questions around cognition to anti-stigma activities, screening, assessment and supporting people who have a diagnosis with their management and care, in community and across the health and social care system. We do have hundreds of staff and thousands of volunteers, always keeping people living with dementia and their care partners at the centre.

You heard a little bit more about this, but I think it bears repeating: In the journey with dementia, the trajectory is different for everyone. What's similar, unfortunately, are the things that we hear in focus groups: It's scary. It's life-changing in a bad way, uncertain, uncoordinated, terrifying. We did a couple of focus groups just in the early summer and they were very, very emotional in terms of people's journey, and a lot of it came down to fragmentation and a lack of coordination.

I think that Bill 121, if passed, will begin to address some of this lack of coordination across the system. I think it is a really important first step in terms of bringing the system together, as the co-sponsors of the bill have spoken about, in terms of integration and crossing sectors.

You've heard a little bit about numbers, and we have some new numbers, as well, from the newest Landmark Study from the Alzheimer Society of Canada, which show a continuing increase in the number of people living with dementia. In Ontario now, we're looking at more than 315,000—still estimated to triple by the year 2050. That doesn't include the 175,000 care partners who spend five million hours per week, or 128,000 full-time jobs of time and effort and energy, supporting people living with dementia. This is a very big challenge now, and it is only going to be getting bigger. That is another reason why we're supportive of Bill 121 in terms of understanding what the current state of dementia care is, developing a framework and looking at some of the elements around training.

In terms of the current state, as suggested in this bill, there is a need to pinpoint the need for change and to prioritize where changes are needed. It also lets us see opportunities for improvement, and that's everything around education, destigmatizing campaigns, screening assessment, diagnosis management and, one day, hopefully, treatment.

I noticed on the agenda that we do have a few folks from industry who are also going to be joining today, so I'm not going to get too much into that but to say that you folks will be aware that Health Canada is reviewing two disease-modifying therapies for dementia, and we're very excited about potentially improving the trajectory of people living with dementia and their families.

That's not going to happen if we don't have a coordinated system that's looking at what's required for screening, that's looking at what's required for diagnosis and, potentially, eligibility for treatment and care. At the same time, a great many people, because of how long it takes, in part, to get a diagnosis of dementia, will not be able to access disease-modifying therapies even when they are approved. The work around putting together a current state and thinking about a future state—anything around readiness for future treatments will also be supporting people who are not going to be eligible and who need support right now.

In terms of the framework, this is something that we are very, very keen on, as it's suggested in the bill. There is coordination happening, but it's not the standard. We think dementia is a chronic disease, not unlike cancer; we do have an entire cancer system—

**The Chair (Mr. Steve Clark):** Mr. Morrison, you've got about a minute remaining in your presentation.

**Mr. Adam Morrison:**—where much of the planning and funding, as well as standards, do happen. The same kind of thing can happen with a framework for dementia care in Ontario.

There are a number of partnerships that I would be happy to speak to, as well, but some of my colleagues are going to be here from the Ontario Brain Institute talking about some work we're doing around cognitive assessments and creating a dementia registry. We're very excited about that. We do believe that a framework will also give an opportunity for a number of these pieces to be spread and scaled across the province.

1110

The work needs to start now. We are very supportive of this bill. We look forward to its passage and working with the government and a number of other stakeholders as we have done in the past in creating the Ontario Dementia Care Alliance, bringing experts together, providing advice to government, and we look forward to continuing that relationship.

Thanks again to the co-sponsors and thank you, Chair, for the time.

**The Chair (Mr. Steve Clark):** Thank you so much for your presentation.

We'll now move to our virtual presenter from the Ontario Long Term Care Association. If you could state your name for Hansard and begin your presentation.

**Mr. Chris Pugh:** Good morning. I'm Chris Pugh, the director of policy and quality at the Ontario Long Term Care Association. The OLTCA represents 70% of Ontario's long-term-care homes, including non-profit, charitable, private, municipal and First Nations homes in communities across the province, from Kenora to Toronto.

I just want to thank the committee for the opportunity to discuss Bill 121 today, and I particularly want to thank MPP Smith and Minister Kusendova-Bashta for sponsoring this bill.

As was said in the House, private members' bills are often personal, and I'm here today because for long-term care, this is personal. All of our homes support those living with dementia and their care partners daily: 62% of our residents in long-term care have a diagnosis of dementia, and 72% have some form of cognitive impairment. Working at a long-term-care home and visiting ones across the province, I've seen the value of high-quality long-term care for helping those whose care needs have progressed well beyond what could be supported at home. I've also seen long-term-care homes and their team members striving every day to help those live well with dementia.

Today, I want to speak to the importance of ensuring that those living with dementia and their care partners have the care where they need it and when they need it, and this need is only going to grow. Ontarians are aging quickly. In fact, by 2040 the number of Ontarians over 80 will nearly double, and as we've just heard, the number of Ontarians living with dementia will triple over the next 30 years. Our health care system will need a plan to meet the needs of these Ontarians, and Bill 121 lays out the map to supporting our aging population and, particularly, those living with dementia.

The government is already on the path forward with significant investments to help meet this need, including increasing health care workers, the growth of primary care investments in acute and ambulatory care, expansions of home care, and in long-term care, the government's invested to increase the direct hours of care for our residents and committed to modernizing the 28,000 older long-term-care spaces, those spaces built in the 1970s that need to be modernized, and the 30,000 new long long-term-care spaces to meet demand.

These investments are a clear commitment from the government to support our seniors, particularly those living with dementia. Particularly, I can say no other jurisdiction has made this level of substantial investment in building a high-quality, safe, modern, long-term-care and seniors care system. These commitments from the government are critical to ensuring those living with dementia cannot just survive but can thrive in their local communities.

That local communities point—I really want to focus in on a bit: Those living with dementia will need different supports and care depending on how their needs change. With complex ongoing illness like dementia, health care



and housing are often critical pieces to living well. Long-term care sits on this continuum of housing and care. For some living with dementia, staying in their single-family home with the help of their caregivers, their family members, their friends and neighbours will be enough. Some will need more care. About 85% will need home care supports, and others will need housing settings to match their care needs, from naturally occurring retirement communities to purpose-built retirement and assisted living communities.

As CIHI, the Canadian Institute for Health Information, reports, 43% of those living with dementia will need long-term care. Due to decades of underfunding, we have seen wait-lists for services across the continuum grow, versus today 45,000 Ontarians are waiting for the 76,000 long-term-care spaces in the province.

With the government's commitments to expand our health care system, we'll just meet the need for long-term care. Ensuring those living with dementia have access to care, especially if they have complex needs that can only be met in long-term care, means we need to continue the government's work to expand capacity across the whole care continuum. By focusing on all parts of the continuum, we can continue to ensure that those living with dementia and our seniors have access to housing and care within the communities they know, the communities where they raised their children, where they worked and are leaders, and where they can continue to participate as much as they are able.

Importantly, those living with dementia have surrounding them a circle of people helping them live well and focus on what matters, from unpaid caregivers or care partners like family members and friends and neighbours, to health care and social support workers. This circle is an essential element to providing good care to those living with dementia, and right now, that circle is strained. CIHI reports that, on average, unpaid caregivers of people living with dementia provide 24.5 hours of care per week with 38% of those caregivers currently experiencing distress, and the Ontario Caregiver Organization reports that 67% of caregivers have hit their breaking point.

On the other side, we continue to have a health care worker shortage. In long-term care alone, our analysis shows we need 58,000 additional nurses and personal support workers to meet the growing needs of Ontario's seniors. As we build a system to meet these needs of both those live living with dementia and those aging in the province, we will need respite and supports for unpaid caregivers, and we'll need to grow a nimble health care workforce that can help those receiving care focus on living well. This bill can be a path forward, as I think Adam Morrison said really nicely, to identify those gaps and to really figure out where we need to do more work.

Finally, I want to home in on that idea of living well. Too often, we focus on medicalized models for dementia care, forgetting about the person at the centre. This bill and the work of the government have focused not just on putting health care systems in place, but that those systems focus on improving and maintaining a high quality of life

for those living with dementia. In long-term care, we are seeing a critical shift from more clinical to holistic models of care that focus on quality of life. Particularly, homes across the province are working on implementing emotion-focused models that centre around the resident—not just their clinical needs, but their physical, emotional, social and spiritual needs. This bill highlights a growing focus on person-centred care, and any plan forward should look at tools to enable care for the whole person, whether at home, in hospital or in long-term care.

With the challenge ahead of us, we need to work together. Those living with dementia and their caregivers, all parts and levels of government, the health care system, those working in our health care and social systems, and local communities need to come together to focus on ensuring those living with dementia have supports across the continuum.

**The Chair (Mr. Steve Clark):** You've got about a minute left.

**Mr. Chris Pugh:** Perfect.

Bill 121 is a great map. It's a map for building that framework and figuring out how we can integrate those care systems, how we can come together and work together, how we can identify those the gaps and how we can build around them. It's a good first step and helps build on the government's commitments and move them forward. Focusing on ensuring we have a nimble care continuum that meets both the broader need of our aging population and the needs of those living with dementia is critical for Ontarians today and tomorrow.

**The Chair (Mr. Steve Clark):** Thank you very much for your presentation.

We now have our final presenter in this section this morning, the Alzheimer Society of York Region. If you could introduce yourself for the purposes of Hansard, and you may begin.

**Ms. Kari Quinn-Humphrey:** Good morning. I would like to thank the standing committee for accepting my request to speak today. My name is Kari Quinn-Humphrey. As the CEO for the Alzheimer Society of York Region, I am here representing over 21,000 people who are currently living with dementia and their caregivers in York region.

I support the passing of Bill 121. As someone who has worked in health care my entire career and with three people in my own family with dementia, I know with great optimism that with the passing of this bill, we can finally begin to develop a framework for consistent, efficient, quality dementia care—a framework that can create pathways to standardized care, create equity across communities and, most importantly, give everyone a fighting chance at a supportive dementia journey.

I want to share my personal experience with an Ontario health care system pathway which turned something unknown for me into a positive experience that I would like to see replicated for people living with dementia and their caregivers. When I became pregnant with my first child, I went to my doctor for confirmation. I took note that she filled out a ministry form and sent it off to indicate that I was pregnant, with the expected due date, my age

and my health status. This basic action was the first step of the pathway for having a child in the Ontario health care system.

Throughout my pregnancy, certain triggers and milestones opened doors and decisions about my personal journey and how it would look. There was my first ultrasound, when I could decide on a home or hospital birth and on a midwife or doctor. I was offered ultrasounds at various stages, and as I came closer to my due date, I was given increased monitoring. This is an example of an existing Ontario clinical pathway, and it worked. But it didn't stop there; I was given follow-up with a nursing clinic and a mom support group once the baby was born, all provided by the government. I was supported in ways that I didn't know I needed yet.

Across Ontario, any pregnant woman with an OHIP card, no matter the colour of her skin, the language she speaks or her household income, has access to this pathway: equal access, organized access and efficient access. It also wasn't a one-size-fits-all pathway; a high-risk pregnancy and a risk of diabetes all triggered different decisions and guidance surrounding my health care. I felt valued and supported.

**1120**

But I kept asking myself throughout this entire experience: Why don't we have a similar system in place for a person living with dementia and their caregivers? And I am still asking that same question.

In York region, the caregivers I encounter need and deserve such a pathway for dementia care. Notice I say "caregivers," as they are the persons who take the brunt of the care and navigate the system. They must not be forgotten.

I want you to picture our most common scenario at the Alzheimer Society: an adult daughter supporting her mother living with dementia. They go to the doctor because the daughter is now struggling with the changes in her mother's needs. For her, there is currently no standard pathway for dementia care, so she does her best. Her mother's doctor will give guidance based on their knowledge of the patient, but there isn't time to discuss the daughter's needs. She researches online when she has a free moment, but it isn't clear what she needs to do next.

The daughter might find the Alzheimer Society of York Region online and call us with some questions. We tell her about the options available in our region. Some cost money; some don't, but we guide her so that she can put the services into place.

By the time we received her phone call, most likely, she is exhausted, halfway through the disease process and burning out. She has been doing it alone, seeking the puzzle pieces she needs for her mother, because there's no road map for dementia care. To go back to my original example, it would be like having your first doctor's appointment when you are eight months pregnant.

Fortunately, in York region, she has access to a day program and can attend a caregiver support group. She can talk to other caregivers and learn from their experience. Everyone's dementia journey is completely different. The

Alzheimer Society First Link Care Navigator connects her to other local agencies and gives her the numbers to call to receive some respite and home care. The daughter has been forced to create a health care pathway herself based on the pieces of the puzzle she put together.

Recently, we had a case that involved a couple who had no children. The wife had dementia, and the husband was supporting her alone. The neighbours called the Alzheimer Society, as they saw the house was neglected, and he had driven into the garage door from sheer exhaustion. They were malnourished. She was incontinent and truly struggling.

She started going to our day program. We connected him to home care and Meals on Wheels. He wished he knew about us earlier so that the end of their lives wasn't in such turmoil.

Now picture an experience with a dementia care pathway. You are concerned about your memory. Through a standardized cognitive test, they recognize the signs of dementia, and they send off a form to the ministry. Now you're on a path. The doctor is triggered to ask, "Do you have a caregiver? Do you live alone? Do you have other health issues? What supports do you need to remain safely in the community? Can you continue to drive safely?" You no longer need to guess when it is time to go onto the long-term-care wait-list or get in-home care, and we don't need to worry—

**The Chair (Mr. Steve Clark):** You've got about a minute remaining.

**Ms. Kari Quinn-Humphrey:**—about caregiver burnout anymore because the supports are offered. All parts of the dementia journey that, currently, Ontarians have to sort out for themselves by piecing together the information.

The truth is, in York region, we are all doing the very best we can to hold on to these puzzle pieces for our community. Agencies like ourselves can act as guides. We can support you locally, build connections and make sure you don't get lost. But we can't control when you enter our system, and we need a framework to put the puzzle pieces together.

Dementia cases are increasing. I don't want to think about what will happen in the coming years if you don't pass this bill. For this dementia pathway to happen, we need a framework for improving dementia care, and the first step to realizing this is passing Bill 121.

**The Chair (Mr. Steve Clark):** Thank you very much, the three of you, for your presentations.

We'll begin with the first seven-and-a-half-minute round for the official opposition. MPP Andrew.

**MPP Jill Andrew:** Good morning, and thank you very much, Adam, Chris and Kari for your presentations. I would like to thank you all at your respective organizations for the hard work you do to support our families and our communities.

Mr. Morrison, we are neighbours, as you may know, and I am personally indebted to the work for a variety of friends and family and community members who are living with Alzheimer's. Alzheimer Society of Ontario is

also an invaluable source to caregivers as well, so I appreciate that.

Kari, you mentioned that we need a standard pathway for dementia care, and I want to say that I agree with that wholeheartedly. This bill, Bill 121, is certainly a nod in the right direction, as I expressed to the minister and to MPP Smith.

I want to ask you all, and I'll ask Adam to start and then we'll go to Kari as well: Can you highlight for us how important it is to have efficient staffing and to have efficient support for the caregiver? How important is that for the Alzheimer's patient, for the person living with Alzheimer's? How important is it for their health care providers and for their caregiver to be whole and to feel supported?

**Mr. Adam Morrison:** I guess the easy answer is, it's very important. If the caregivers don't have the support that they need, they often become patients themselves. We see this especially in the older adult population of folks living with dementia, where sometimes it is someone else who has two, three, four, five-plus chronic conditions who is caring for someone living with dementia, so supports for caregivers are very important. That's why we do have programs that are specifically for people living with dementia, we have programs that are specifically for care partners, and we also have programs that support both as a kind of dyadic intervention. One of the dedicated supports we have in a great many of our societies is specifically supporting care partners with approaches around strategies for supporting someone living with dementia but around their own resilience, around their own mental health and putting those pieces together.

At the Alzheimer Society, we understand the many different needs of people living with dementia and their care partners and often do think about them—where people are fortunate to have a care partner, because not everyone does—as a dyad, so not just what does this person need but what does this dyad need, what does this group, this family need to be living well in the community.

**MPP Jill Andrew:** Thank you. And thank you also for the work you do to support 2SLGBTQIA+ communities as well, because Alzheimer's does not discriminate. It most certainly doesn't.

And yourself, Kari?

**Ms. Kari Quinn-Humphrey:** It is very important to ensure that staff are appropriately equipped. There is a direct relationship between the quality of care that is provided to a person living with dementia and the training that a staff member has and the resources that they are given, absolutely. We do have training at the Alzheimer Society for personal support workers specifically and for other front-line health care workers because we recognize that there is a direct relationship.

It is very, very important in this bill to be looking at that curriculum for personal support workers moving forward. In a past life, I trained personal support workers on dementia care and could see the lightbulbs going off in the room, and the relief that they would feel when they understood some of the tools that they could utilize to reduce the

triggers that would cause behaviours in persons living with dementia, because the person would become frustrated or become disoriented. By orienting them and providing them with that supportive environment that the staff can do through that education, it's very, very valuable and it creates a better environment for that person living with dementia.

**MPP Jill Andrew:** Thank you. And Chris as well, too.

**Mr. Chris Pugh:** Thank you for the question. I think Kari and Adam covered it really nicely, but we need both, and I think I spoke to that. It's a circle of care. You need both. You need good staffing, and then you need to make sure that your unpaid caregivers or your care partners have supports. I think in long-term care, what we often do is that we feel like we're kind of catching the gaps when someone finally enters into long-term care. We have caregivers who have just been stressed, distressed and they're coming to long-term care and there's a lot of guilt about that, but there's also a bit of relief. There's a moment where we do a lot of work with our caregivers to support them, and I think social workers in our homes do a lot of work to help our family members and our supports, as well as helping those living with dementia to transition.

To answer your question, both are critical, and I think staffing is an important part. And I think Kari said really nicely that training piece is so important, and training our staff members is important.

**MPP Jill Andrew:** Thank you very much, Chris. Because, make no mistake, curriculum is important. Many of us on the opposition bench, myself included, we're teachers, we're professors, we're educators. No one's going to question whether or not curriculum is important.

**1130**

As we've belaboured earlier, adequate pay—a living wage in my community of Toronto—St. Paul's, where a one-bedroom is \$2,700 a month, means that if we are not adequately respecting, protecting and paying our nurses in home care, in long-term care, in our hospitals, we can have state-of-the-art curriculum, but they simply will not be there. We've seen a privatization agenda with this particular government where many of these workers are jumping the border and going to other countries. We need them here to support our Alzheimer's patients. Thank you so much.

How much time do I have left?

**The Chair (Mr. Steve Clark):** You've got a minute 20.

**MPP Jill Andrew:** Oh, wonderful, wonderful.

Can I ask a question about operating funding and any supports that you all receive from the current Ontario government? I'm wondering if Adam can talk about the Alzheimer Society of Ontario. What does your staffing look like? Are you all overwhelmed? Are things running smoothly? And then, from yourself, Adam, we'll go to Kari as well. Thank you.

**Mr. Adam Morrison:** Sure. So, I mean, we're certainly not bored—very, very busy at the Alzheimer Society of Ontario. We have approximately 50 staff, and those are folks who work across the province. And, of course, that's not including the 26 local societies.

It's a very busy time in terms of the work that we are doing, thinking about how we're partnering with different organizations across health and social care, supporting local societies in the programs that they have, helping them build or to scale and spread. Folks heard about the DREAM program already; that's now in 15 hospitals, and there are others who are interested as well. That's a lot of the work that we do. So it's certainly quite busy right now, and we do rely on a lot of partners, not just our local societies but our counterparts in other provincial organizations as well to work together.

**The Chair (Mr. Steve Clark):** Thank you, MPP Andrew, for this round.

We'll now move on to MPP Clancy. You've got four and a half minutes.

**Ms. Aislinn Clancy:** I have a question to start with for Adam. I was at our AGM for the Waterloo Wellington Alzheimer Society and had the honour of listening to Ngozi, one of your excellent staff, share a little bit about equity. My hope is that the bill—I know MPP Kusendova-Bashta is very excited about culturally specific care for our seniors. How do we weave that into this bill, given your expertise in ensuring that BIPOC, 2SLGBTQ+ folks and folks with different disabilities and incomes are considered in a holistic view?

**Mr. Adam Morrison:** That's a great question. I wish Ngozi were here right now because she would give a much better answer. She is more articulate than me as well in getting that out, so I'm glad that you got to speak with her and to hear from her.

We do have a health equity framework. We'd be very happy to share some of that work.

When I look at the bill, there's a lot about all of the folks who will be consulted for the framework as well as for the current state, and I think to kind of reinforce that you'll be speaking with people living with dementia and care partners from a multiplicity of diverse communities and then naming some of those pieces as well, whether you're talking about urban, rural, suburban, remote as well as BIPOC, 2SLGBTQ, a number of Indigenous communities on reserve and urban Indigenous communities. To name that in terms of the consultation I think would be really helpful in terms of weaving that in because it's people's own experiences that they're speaking to. As you know, it's not a one-size-fits-all. This is now culturally competent. There is, of course, a linguistic dimension to that, as well as people's identity, cultural background, religion and where they live as well.

**Ms. Aislinn Clancy:** Thank you. Yes, I echo that, and I really appreciated that that's the work that you do, bringing that message out to communities, especially mine—woohoo.

My next question is for Chris. As we see the erosion of primary care, how do you see the change in the folks that land in long-term care? What I hear in my community: I was at Sunnyside, and people come out of emergency rooms for—not-for-profit, accessible, financially affordable care tends to have astronomical wait-lists, and then we only see folks coming from hospital. I don't know if that's—I don't mean to use broad strokes, but that's a real

thing. Can you speak to how the underfunding of primary care and these wait-lists are impacting folks getting early diagnosis?

**Mr. Chris Pugh:** I think that there are a couple of pieces there that are useful to speak to. One is that the province is covering decades of underfunding in our health care system, so what we're seeing, particularly in long-term care, is long wait-lists and then, as you're highlighting, a growing alternative level of care in our hospitals. So we do see more people coming into long-term care from hospital. Our latest data says that about 75% of our residents come from hospital. In the past, it used to be about 60%. I'd say today, once we get that newest data set, it's likely a lot higher.

**The Chair (Mr. Steve Clark):** You've got about a minute left, MPP Clancy.

**Mr. Chris Pugh:** I think what we're seeing is residents coming with less supports in community, less care and, particularly, a hospital is not a great place to be. That's not how we want people coming into long-term care. We want people coming from community with appropriate supports and transition. So shifting that, ensuring that we have those supports in community and that people have a pathway into long-term care that's not through an emergency room is critical.

**Ms. Aislinn Clancy:** If we don't have adequate family doctors, how is that going to happen?

**Mr. Chris Pugh:** Primary care is a significant problem across Canada. Our health HR surges are a global problem, it's not just Ontario. I think we'll need to work on supporting primary care, growing those pathways and supports for our primary care doctors. We also have primary care doctors in long-term care, our medical directors as well as our attending physicians of primary care, and we do have significant issues maintaining those levels and supporting those team members and ensuring we have doctors to care in long-term care. So it's a wider system problem that we want to support.

**Ms. Aislinn Clancy:** Do you agree that maybe that's where people land—in emergency rooms? Have you talked to people who don't have a family doctor?

**The Chair (Mr. Steve Clark):** MPP Clancy, unfortunately, that's it for this round.

We'll move now to the government's seven and a half minutes. MPP Dixon.

**Ms. Jess Dixon:** I thank all three of you for coming. I'm not sure who to direct this with, either to Mr. Morrison or Ms. Quinn-Humphrey, possibly. MPP Laura Smith was talking in her presentation a lot about the Ontario DREAM program. I'm not as familiar with this area. I'm wondering if you can talk a little bit more about what that is. I see Ms. Quinn-Humphrey nodding. If you can tell us a little bit more about what that is and how this bill plays into that with the framework etc.

**Ms. Kari Quinn-Humphrey:** They're embedding a resource consultant specializing in dementia in the emerg department. So they're there Monday to Friday, 9 to 5—so we're not 24/7 at this point—but they're an employee of the society and they are providing support to the staff in

the emerg department. If you needed to draw blood and it was a person with dementia, they would be distracting that individual with an iPad or a music player or a tactile toy—I don't want to use the word "toy," but a therapeutic apparatus that they would use, or they're just there to distract them.

They're also there to support the caregiver who the emerg staff do not have the opportunity to support in the moment, so that caregiver is receiving support from that dementia resource consultant. The other part to it is, that consultant has hours attached to them to help that family member to be redirected back out, once they're medically stable, into the community with immediate supports. So they look at the individual, they look at the circle of care that is needed for that caregiver and that person to be diverted from going into a hospital bed and going back out into the community, which is exactly where they want to go.

A lot of times, a person with dementia and the care partner ends up in the emerg department more out of the burnout from the caregiver than the actual medical needs of the person with dementia that's in the bed. This is an opportunity for that dementia consultant who can specialize in the moment, redirect that person back out to the community with immediate resources, connect them with other resources, and meanwhile supporting the staff, who don't have a lot of time and can't slow down enough for that person in the bed who has dementia, a lot of times. So there's this lovely synergy with the staff and the dementia resource consultant, and with the caregiver building that circle of care.

**Ms. Jess Dixon:** That's fascinating. I actually was speaking to Professor Lin Haag yesterday, who works in intimate partner violence and brain injury, and she was talking about the social work program—of training social workers to work with intimate partner violence victims that have traumatic brain injuries because their personalities may not trigger people that there's something going on necessarily, but it makes it very difficult. Is that sort of similar here, where you've got the two benefits? One, you have the consultant who's able to make sure that that pressure is off the caregiver in the situation, off the service, the health care provider in that—I guess, actually, it sort of ties into what you were saying a little bit earlier.

1140

Can you explain a little bit more what you were saying, when you used to do training, of what that looks like when a service provider is sort of twiggled into different ways to deal with somebody, or tools and tips, I guess?

**Ms. Kari Quinn-Humphrey:** Sure. I'll try to go really fast. But think of a person who goes back in time in their memory. Their long-term memories are what they hold on to. So they might think they are 25 years old versus 85 years old because that's what their memories are telling them that they are.

Explaining to a staff member to go to where they are in the disease process—instead of arguing with them to say, "No, it's 2024," instead of going back the 60 years that they need you to go—go back the 60 years. Talk to them

about being a young person. Talk to them about their young children instead of the 60-year-old sibling or adult child who's out in the waiting room. Those simple little changes that you can make in how you approach the individual to de-escalate the situation instead of causing greater confusion is just a simple, simple mindset change for that staff member. If they see that resource consultant modelling that, they can replicate that when that consultant is not there. So it's building the capacity of the staff in the emerg department.

**Ms. Jess Dixon:** That's fascinating. I can really see how incredibly useful that is.

Chair, I will end my questioning there.

**The Chair (Mr. Steve Clark):** MPP Smith?

**Ms. Laura Smith:** Thank you, and through you, Chair: First of all, I have to thank all the participants today. I truly value your opinions.

Ms. Quinn-Humphrey, you paused on something that really was very interesting to me—you talked about the different levels of care and an enhanced dementia education, improved communication, de-escalation. Just like you, my mother was in the 30 years ago and not in the now. I'm just wondering, how do you believe reviewing the PSW standard could potentially help reduce the stigma in care for those living with dementia?

**Ms. Kari Quinn-Humphrey:** You have personal support workers right now who do not want to work with people living with dementia. They specifically ask to not work with them for a multitude of reasons. I think a lot of it is fear and uncertainty and not having the confidence to feel that they have the tools they need to support that individual.

Taking the time to educate that personal support worker at the college level is very valuable. You will have people who will have never met someone with dementia coming into the PSW program. So it's really important that they have (a) the opportunity to understand the disease process, and (b) to understand some of the resources that they can utilize and the tools. We have physical tools that we give them so that when they're back on the floor—

**The Chair (Mr. Steve Clark):** There's one minute remaining in this round.

**Ms. Kari Quinn-Humphrey:** —working with someone with dementia, they have the opportunity to continue to learn and to grow.

So I really do believe that the personal support worker having that information is valuable and will reduce the concerns and empower staff out in the community.

**Ms. Laura Smith:** Thank you.

I'm going to pass my time over to Minister Kusendova-Bashta.

**Hon. Natalia Kusendova-Bashta:** I will ask my question this round, and perhaps you can answer it next round. My question is to Adam. Nice to meet you. Your predecessor Kyle was doing such an incredible job. He was on both of our speed-dials. So you have big shoes to fill.

My question will be about the disease-modifying agents. I know we have Eli Lilly coming today as well as Eisai, and I think we're starting to see that light at the end of the

tunnel. So perhaps in the next round you can tell us about the exciting research that's happening, what this means for folks living with dementia and how this can impact their care pathways.

**The Chair (Mr. Steve Clark):** Thanks, Minister. We'll have to come back to that question in the next round.

The government's time is finished, so we'll now move to the official opposition. MPP Vaugeois, you've got seven and a half minutes.

**MPP Lise Vaugeois:** First, I want to thank you for being here. We have a very wonderful Alzheimer Society in Thunder Bay—understaffed and underfunded, I have to say. I know that all the non-profit organizations in my region had a large meeting about six months ago in which there was a lot of discussion about lack of funding for not-for-profit organizations. I won't ask you to go into the details of your specific situation, but I know that's a serious concern in Thunder Bay, the lack of increases to base funding and lack of increases even for inflation.

I want to put this question to the three of you: Because it is in Alzheimer Society recommendations, I wonder if you can speak to the importance of equalizing wages between hospital, home and community care workers, and how that affects the kind of care that people are able to receive in their respective contexts, particularly at home.

Can we start with Kari? Then let's go around this way and we'll end with Chris online.

**Ms. Kari Quinn-Humphrey:** I can't speak to in-home, because we're a community-based agency. We're not going into people's homes directly outside of two individuals who do some active-living respite.

It is true that there is a discrepancy between the wages of staff in the community and in hospitals. It is true that there are times we have had some problems hiring staff who are needed with the skills that we need. I think that is a universal problem, as to the point made earlier. We're doing well with the resources we have. We also utilize volunteers to help us, and donor dollars as well.

**Mr. Adam Morrison:** I don't have a lot to add to what Kari said, except that it's not a secret that there's a disparity in wages depending on where you are working. I think a lot of advocacy, especially when we think about people living with dementia, is that this is very challenging work regardless of where you are. It is, as Kari said as well, a recruitment and retention challenge. Other folks have spoken to people moving from one sector to another, so I think that's something that's quite well known and is at least as important in the community as it is in other care settings.

**MPP Lise Vaugeois:** Thank you, Chris?

**Mr. Chris Pugh:** I don't have too much to add; I think the others have spoken really nicely. There is a bit of a disparity, but we also know, talking to some of our partners, our team members, that there are other changes. Like Adam said earlier, a lot of this work can be quite difficult, so it's ensuring our team members have appropriate supports. In long-term care, we have Behavioural Supports Ontario who really support our homes to ensure that our team members are trained and have the skills.

The other thing that we've really seen a lot of success with on the recruitment side is living classrooms, which our ministry has really expanded in Ontario. What we've seen is that once team members are able to work in a home, train in a home and learn what it looks like to actually do support for those who are aging, particularly those living with dementia, they actually want to stay, so we have greater supports there as well.

**MPP Lise Vaugeois:** I wonder if you can—this is kind of a practical question. I know from my own family experience that when respite was offered, it often meant taking the person with Alzheimer's out of the home, somewhere else, and that's actually terrifying for the person with Alzheimer's to be moved out of their safe space.

So I'm just wondering what options are available at this point. Can you get respite in the home for caregivers?

**Ms. Kari Quinn-Humphrey:** We have three adult day programs that we run out of York region in different areas, because it's such a large region, and there is value in having the person come out of their home, be social and be able to interact with others, to allow that caregiver to have a few hours to themselves to be able to run their errands and be able to have a bit of a breather, where they don't have to be constantly concerned about their individual; they know they are in a safe environment.

On the flip side, that person with dementia gets a chance to be social, get out of their home, be with other people, interact. There's lots of dancing in our day programs, lots of music, lots of breaking bread and having a social time together.

Although I understand the question around not wanting to be leaving your home, there are situations where people don't feel comfortable to leave their home anymore because it's the only space that they recognize is safe. So, yes, there is the absolute need for that respite to be going into someone's home, in the situations where persons living with dementia are only wanting to be there.

**MPP Lise Vaugeois:** Thank you.

**Mr. Adam Morrison:** If I can just add very briefly to that: Depending on the society—and we continue to roll out more programs around respite, and this comes to the dyadic piece I was talking about before—supporting a person living with dementia can be providing respite for the care partner. We do also have, and are building more, in-home respite programs as well. That's actually on a peer support model of people who have been care partners in the past and perhaps their loved one has died, that they can come to the home and be there with the person living with dementia and care partner can have respite, whether they're elsewhere or at home.

**1150**

So it really does depend on the person. Sometimes it can be very disturbing to take the person out of their space. The kinds of programs that Kari and her colleagues run around the province are structured so that they're providing that social activation in a more comfortable space, and if someone does have a negative reaction, there are folks

who are there who have expertise to support them as well. So we do both in-home and—

**MPP Lise Vaugeois:** That's excellent, thank you, because I appreciate both contexts.

**The Chair (Mr. Steve Clark):** You've got about a minute left.

**MPP Lise Vaugeois:** I'm just wondering about the DREAM program. What would it take to get it in other parts of the province?

**Ms. Kari Quinn-Humphrey:** Money—so, York region doesn't currently have the DREAM team right now. It is the hope and dream to have that, no pun intended.

**Mr. Adam Morrison:** Yes, and just to say the DREAM program exists in 15 hospitals in the Ontario Health West region right now, and within that region, unsolicited, we have another 18 hospitals who have said they would like to run the program. And, yes, it's funding for the dementia resource consultants.

**MPP Lise Vaugeois:** So just to be clear, it requires additional funding to make it happen. So professionals are going in as part of Alzheimer's teams or are they volunteers or a combination of both?

**Mr. Adam Morrison:** They're paid staff from the local Alzheimer's societies.

**MPP Lise Vaugeois:** Paid staff, okay.

**Mr. Adam Morrison:** So we would be hiring new—

**The Chair (Mr. Steve Clark):** Thank you. That's the end for the official opposition.

The independent member, you've got four and a half minutes.

**Ms. Aislinn Clancy:** I'm hearing from all of you that there are alarm bells going off, right? You see the urgency of the situation, with the growing number of folks facing dementia and the wait-lists seeming to grow. My understanding is there were funds promised to dementia care a while back, maybe 2021 and 2022, of \$10 million. I guess I worry this is just—I'm optimistic but cautious that we'll have a report that has a lot of great expertise and that there's going to be a price tag. I think all of the solutions we're talking about require investment. I think we can save a lot of money by spending—I don't know what the dollar-to-dollar amount is, but I imagine there's a real benefit to investing in more prevention.

Can you tell me, if you see delays in the implementation of this report that we're talking about, what will that mean to the folks that you serve? Maybe I'll start with Kari.

**Ms. Kari Quinn-Humphrey:** We're going to just keep chugging along with a lot of unknowns, and we're just trying to put the pieces to the puzzle together, as I said earlier. We're doing the best we can. We partner with others. We do what we can. There's a lot more need out in the community, though, that we're not able to reach right now. We are at capacity. We're going to continue—

**Ms. Aislinn Clancy:** What are your waiting lists like? Tell me a little bit about your wait-list, perhaps.

**Ms. Kari Quinn-Humphrey:** I'll give you the example of Toronto. Toronto has an eight-week wait-list to get a phone call back for intake right now.

**Ms. Aislinn Clancy:** That's just intake. Yes, and then you're put on another wait-list, I imagine. Let's say you need—maybe you could give me one example of a wait-list other than the intake.

**Ms. Kari Quinn-Humphrey:** So we've worked really hard to become more efficient in it, but there is a wait-list of approximately three months to get onto a support group—like as a care giver, if you're wanting a support group.

**Ms. Aislinn Clancy:** Okay, thank you.

Do you have anything to add, Adam, to delays?

**Mr. Adam Morrison:** I think the piece around wait-lists is pretty illustrative, and so the longer we continue to work in an as-is space, the greater the waiting lists are going to be. As Kari said, we have an incredible number of folks working for—and multiplied by that number, volunteers with the Alzheimer Society who are working a lot and are, I think, awfully efficient with the dollars that we have in the community support services sector.

**Ms. Aislinn Clancy:** Chris, do you want to add anything if we see a delay? I was just in colleges and universities; there was a blue-ribbon panel. It was fantastic: lots of experts, lots of collaboration. We get these recommendations and then we're kind of stuck, not addressing the alarm bells going off.

Can you share a bit about what the worry is if we continue on the path without action and investment?

**Mr. Chris Pugh:** I think we already highlighted growing wait-lists; I think we really want to highlight the caregiver distress. We'll see a number of people who are having their own health issues due to caregiver stress.

**The Chair (Mr. Steve Clark):** You've got a minute left.

**Mr. Chris Pugh:** I think the other big piece, though, and the nice thing about this bill is the bill can identify some frameworks where we can integrate better, where we can actually use current resources. The government has invested heavily, particularly in long-term care. How can we leverage those resources to support across the continuum in other places as well? If we get a good framework in place, we might be able to integrate it and use the resources we have today as well.

**Ms. Aislinn Clancy:** Awesome. Just a final one for, perhaps, Adam: Do you consult much? Do you hear much from PSW minimum wage earners working for the private sector? Do you hear their voices at all in the work you do?

**Mr. Adam Morrison:** I don't have a good answer to this question, because I'm quite new to my position.

**Ms. Aislinn Clancy:** Okay, fair.

**Mr. Adam Morrison:** We do hear from a lot of our staff, sometimes where folks do leave for a position that is higher paying. That's not a secret in the community sector. I would speculate that would not be inconsistent with folks who are—

**The Chair (Mr. Steve Clark):** Thanks, MPP Clancy. We've completed this round.

Now, the minister posed Adam a question in the last round. Minister, did you have anything further to say before he answers?

**Hon. Natalia Kusendova-Bashta:** No. I would just love to hear more about the disease-modifying agents and the very exciting research that's happening in the space right now.

**Mr. Adam Morrison:** I would love to speak to that in the context of how it can be supported through a dementia care framework; there are people much smarter than me who are lifelong experts on the research who you will hear from shortly.

We are excited. There are two disease-modifying therapies in approvals right now with Health Canada that can slow the trajectory of folks who are eligible for the medication. In terms of why we're excited, it's because that can significantly impact, in a positive way, some people's lives.

One of the reasons that we are concerned and why we are very supportive of this bill is because we believe a framework is going to be necessary for anyone to be able to get the drugs. I was in Philadelphia at the Alzheimer's international conference, and in the opening keynote from the president and CEO of the Alzheimer's international association she said that if we don't do something—she was talking about America and she was talking about the world—to be ready for disease-modifying therapies, we are about to enter the greatest era of health inequity we have seen in our lifetime.

And so, what that means for us is figuring out early detection so that screening, assessment and diagnosis are going to get us to the point of understanding whether someone is going to be eligible for one of the drugs or not—and we are supporting people whether they're eligible or not, regardless of what their trajectory is.

We know in Canada that we are not providing diagnosis to people living with dementia early enough in their journey, as I understand it, that many folks will be eligible for the drugs. This bill is really important so that we can figure out and make those investments to fill the gaps to be seeing people far sooner than what Kari was describing, far sooner than that eight months into your pregnancy analogy, so that we are seeing people, supporting them and getting them a diagnosis and along the pathway much sooner, and that readiness work has to happen now.

**The Chair (Mr. Steve Clark):** MPP Pang.

**Mr. Billy Pang:** Thank you for the presentation. Earlier in your presentation, you mentioned that different patients have different situations, so looking at personalized or person-centred care is very important. As person-centred care has emerged as a leading approach in the treatment and support of individuals with dementia, could you please explain what person-centred dementia care involves and what differentiates it from a more traditional care model?

**Ms. Kari Quinn-Humphrey:** Person-centred care is looking at the person living with dementia and ensuring that they're at the centre of all the decisions that are made based on what their wants and needs are versus what the caregivers' wants and needs are versus what the staff members' wants and needs are. It's really ensuring that we're looking at the person standing in front of us and ensuring that we're considering everything that they

would want for that particular individual, is basically what it comes down to.

We have a model where we look at the physical needs, the intellectual needs, the environment, the social needs, recognizing that the religion of an individual, the culture of an individual, needs to be taken into consideration for care. As an example, our adult day program doesn't always have culturally specific food for an individual that we would prefer to be able to provide but aren't able to at this point. It's about having that person at the centre of the care.

**Mr. Billy Pang:** Yes, I can tell, especially—I'm from York region as well, with the diversity—there are a lot of visible minorities with different cultures, different languages, different backgrounds.

On top of that, is there anything to add from Alzheimer Ontario?

**Mr. Adam Morrison:** I think that the only thing I would add, just to reinforce, is it's a need-to-have and not a nice-to-have. In the example Kari was speaking about, if someone is not comfortable coming to a day program, they're not coming back. If they can't find someone they can be with and empathize with, if they can't eat, if they don't feel safe—person-centred care is understanding who that person is and making sure they're welcome in the space for the therapeutic care that they're getting.

So it sounds very nice, and I think people talk about it a lot. We know that it's a need-to-have in terms of people engaging with care. Otherwise, they don't, and that compounds problems for people living in the community or anywhere across the continuum of care.

**Mr. Billy Pang:** Thank you.

**The Chair (Mr. Steve Clark):** Minister Kusendova-Bashta.

**Hon. Natalia Kusendova-Bashta:** I just wanted to ask a very quick question to OLTCA. First of all, I wanted to thank you and Donna and the entire team for being such an incredible partner for our government and for helping us to put policies forward.

I wanted to ask you if you can comment about the BSUs, the behavioural specialized units, that our government has introduced and that we are continuously funding, as well as some of the new models like the butterfly model and the different emotional-based models that are being implemented across your membership.

**Mr. Chris Pugh:** Absolutely, and thank you, Minister. Thank you for the partnership, as well.

I think particularly BSUs have been such an important piece of care that the government really has expanded and grown, and BSUs really help residents who may be having issues transitioning into long-term care, having responsive behaviours and expression and just need extra levels of support to transition. BSUs have been really critical for that, to help people transition to long-term care, do well and live well, and then once they're able to do that, they can move to a different home. It's just an important part of that continuum of care, particularly as people have complex needs.



I think the other piece that's really important is speaking to those other models, and I kind of hinted to them in my presentation, those emotion-focused models. For me, that is the realization in a lot of ways of person-centred care. Those models don't just look at the clinical needs of someone, but they look at the holistic needs. We look at everything someone needs. We recognize as part of those models that a long-term-care home is a home. This is your home first, and what we do in long-term care is about living first. And so, especially with those living with dementia, how do we help them continue to live well? How do we help them continue to do the things that they love and want to do? And how do we help this person—

**The Chair (Mr. Steve Clark):** There's one minute remaining.

**Mr. Chris Pugh:**—uphold their values and their culture as part of that care?

**The Chair (Mr. Steve Clark):** MPP Pierre.

**Ms. Natalie Pierre:** My question is for Chris Pugh from the Ontario Long Term Care Association. It was just really building on something that you said earlier that landed on me, when you were talking about resident-centred care and you said, "not just survive, but thrive." I was wondering if you could just take a moment or two and maybe just share your opinions and share your perspectives on how we make that happen.

**Mr. Chris Pugh:** Absolutely. I think what we're seeing in long-term care, the response—the pandemic exposed a lot of cracks in the system. But what it also did, and I saw this in the sector, is it built a fire in the sector where we're just growing and we're really focusing on that quality of life. I'll say, having worked in a long-term-care home and thinking about that individual resident that I would help read the newspaper to, because that's what he cared about, I think that—

**The Chair (Mr. Steve Clark):** I'm so sorry. That concludes our time today.

I thank all three of our presenters. I want to thank members of the committee. The committee will stand in recess until 3 p.m., when we will resume public hearings of Bill 121.

*The committee recessed from 1204 to 1500.*

**The Chair (Mr. Steve Clark):** Good afternoon, everyone. I'll call the Standing Committee on Social Policy to order. We're meeting to resume public hearings on Bill 121, An Act to enact the Improving Dementia Care in Ontario Act, 2024.

To our presenters, I just want to make sure you're heard and recorded for Hansard, so just speak slowly, clearly into the mike.

I want to remind the presenters that you're going to have seven minutes each for your presentation. After we've heard from all of you, we'll then go into the rotations of questions and comments. We have 39 minutes of questions for the members of the committee. They'll be apportioned into two rounds of seven and a half minutes for government members, two rounds of seven and a half minutes for the official opposition and two rounds of four and a half minutes for the independent member.

Procedurally, I will say to the committee that there are two presenters this afternoon, the Alzheimer Society of Peel at 3 o'clock and Eisai Ltd. at 4 p.m., that have two presenters. I'll need to get unanimous consent from the committee—I might as well do it right now—that both presenters for those two groups be allowed to present. So is that agreed upon by the committee? Agreed? Okay, perfect. That's wonderful.

ONTARIO BRAIN INSTITUTE  
ALZHEIMER SOCIETY PEEL  
MINT MEMORY CLINIC

**The Chair (Mr. Steve Clark):** The 3 o'clock time slot has the Ontario Brain Institute, the Alzheimer Society of Peel and the MINT Memory Clinic. I will first call on the Ontario Brain Institute. I'll ask you to say your name and title into Hansard for the purpose of recording.

Your presentation begins now.

**Ms. Christa Studzinski:** I'm Christa Studzinski from the Ontario Brain Institute. I'm the director of business development and partnerships. Thank you to the Chair and the members of the standing committee for the opportunity to speak today in support of Bill 121. I'm just going to start my timer, so I make sure that I stay on track.

Imagine if every person over the age of 60 could access a free five-minute test to check their memory and cognitive function. We could then reassure seniors experiencing normal forgetfulness that they're okay and prioritize the seniors experiencing cognitive changes for additional testing.

The Alzheimer Society of Ontario and the Ontario Brain Institute have partnered to validate one such test in the community. We're also looking at the barriers and the facilitators to implementing a test like this so that, if it works, we understand how to go about it. This is why Bill 121 is so important. It and the resulting dementia framework will help make sure that tests like these get deployed in a coordinated and cohesive fashion across Ontario to improve dementia care for all Ontarians.

I'm not going to repeat the statistics that MPP Smith and Minister Kusendova, Adam, Chris and Kari shared this morning. You understand the scope of the problem. I'm here today to focus on three things:

(1) I want to bring forward to the committee the global perspective on dementia.

(2) I want to convey the importance of Bill 121 to signal Ontario's commitment to lead globally while making an impact locally.

(3) I would like to paint a picture of what could be possible if/when—I'm being cheeky—Bill 121 is passed by the Legislative Assembly.

Before I jump into the good stuff, a little bit about the Ontario Brain Institute. Some of you are aware of the work that we do. We've had the pleasure of meeting with a few of you in the past. For those of you who don't know us, the Ontario Brain Institute is a not-for-profit funded primarily by the Ontario government through the Ministry

of Colleges and Universities. OBI is advancing evidence-based brain health solutions. We partner across the ecosystem to move innovation from the lab into the community where people are living with and receiving care for their brain disorders. Since 2010, the Ontario government has provided us with just over \$251 million. OBI and its partners have leveraged this funding into an additional \$820 million to support brain-related activities in the province. Many of these are related to dementia.

I've been fortunate to be with my organization for 13 years. Before that, I grew up in the neurodegeneration space, so improving brain health and, more specifically, transforming dementia care is personal to me—like many others you have and will hear from today.

The timing of today's conversation could not be any more perfect. Earlier today, a global collaborative on Alzheimer's disease actually presented a call to action on dementia at a side event to the G7 Health Ministers' meeting in Ancona, Italy. The Ontario Brain Institute and the Alzheimer Society of Ontario are engaged in this global movement. In fact, both of our organizations added our names in support of the call to action. This engagement, combined with Bill 121, creates an opportunity for Ontario to have a more prominent seat at a global table and to attract global resources to fund innovation and health system preparedness projects right here in Ontario.

The time for action is now. We've made significant advances in the detection, diagnosis and treatment of Alzheimer's disease, and the momentum keeps building. This is going to increase the demand for cognitive assessments and early detection. We need a dementia framework to make sure that these advances are made available across the province in a patient-centred and cohesive manner.

The passing of Bill 121 will be a signal that Ontario wants to lead globally while making an impact locally. It will signal to local partners that we need to come together as a united front to prioritize dementia care.

OBI supports Bill 121. We support the bill's emphasis on prioritizing person-centered, coordinated and cohesive care. We need to raise the tide and lift all boats, rather than focusing on fragmented, siloed and inaccessible care, much like we did for cancer many moons ago.

We applaud the reference to the collection of standardized data elements that will help fill evidence gaps and improve the overall quality of care. OBI has a track record for establishing and deploying standardized data elements through its clinical research programs and we're currently partnering with the Alzheimer Society of Ontario to establish dementia-specific, standardized data elements in the community setting.

Finally, we would like to recommend that the committee also consider including an emphasis on the need to test and evaluate alternate care pathways that make use of made-in-Ontario, evidence-based solutions and leverage community organizations, pharmacies, optometry clinics, allied health services, even banks and libraries and other organizations, to alleviate wait times and create a spider-web for care that prevents our seniors from falling through

the cracks and helps prioritize specialty care for those who need it most.

Why? Why should we do this? Because there are pockets of excellence in dementia care in Ontario.

**The Chair (Mr. Steve Clark):** There's one minute remaining.

**Ms. Christa Studzinski:** Some of these reflect a change in thinking about how care should be delivered. Bill 121 and the dementia framework will help identify these strengths so that we can scale them.

I started with an example and I'm going to end with an example: Imagine if we could predict Alzheimer's, or we could predict who has Alzheimer's pathology in the brain, by simply taking a picture of their retina in an optometry clinic. We could then prioritize brain imaging for people who are more likely to be positive for that pathology.

The Alzheimer Society, the Ontario Brain Institute and Dr. Sharon Cohen have been working with a company called RetiSpec to advance this technology, a made-in-Ontario start-up. If approved by Health Canada, we'll be able to leverage the dementia framework to make sure that this eye test gets deployed across Ontario. Imagine.

This is why the Ontario Brain Institute supports Bill 121. We believe that Bill 121 will signal Ontario's commitment to lead globally while making an impact locally on dementia care. Let's make this our legacy. Thank you for listening.

**The Chair (Mr. Steve Clark):** Thank you very much.

Now we'll go to the Alzheimer Society Peel, if you want to introduce yourselves. Your time begins now.

**Ms. Niké Anna Myers:** Hello, honourable Chair and members of the standing committee. My name is Niké Anna Myers and I'm deeply grateful to speak on behalf of the Alzheimer Society Peel. I would like to share our insights from an organizational standpoint regarding Bill 121.

Alzheimer Society Peel supports families and individuals affected by Alzheimer's disease and related dementias. We promote public and professional awareness while offering various programs and services, including adult day programs, respite care, information and resources, education, support, counselling and behavioural supports. Our goal is to alleviate strain and improve outcomes for individuals, families and health teams. The local chapters are where the vital work takes place, spanning acute care, community settings, emergency rooms, supportive living and long-term care.

**1510**

We're here today because Bill 121 does matter. We support this bill. We know that dementia is the greatest health challenge of Canada's aging society. The numbers generated by the landmark study are alarming. By 2050, more than 1.7 million Canadians are expected to be living with dementia.

Dementia has a disproportionate impact on individuals in the caregiving role. I know this personally as a caregiver to my dad, who lived with frontotemporal dementia, and now professionally as a respite care manager.

What we know: We know that most individuals who develop dementia do not face the challenges alone. Family, friends and neighbours often help support people living with dementia. The people contributing both formal and informal care need support and resources. We see the need to address the public health challenge through the lens of caregiver resilience and caregiver respite programming and providing services in a variety of settings. Our data shows the increased demand for overnight respite, education, counselling, as well as the growing wait-list for day programs scattered throughout the Peel region.

Advancing health programs for the most vulnerable and facilitating an equity lens approach in dementia care is necessary. Representation matters and must include age, income, race, culture, gender, Indigeneity and sexuality, and the implementation of a diversity, equity and inclusion framework. Racially diverse communities in Ontario face barriers including seeking diagnosis, accessing dementia care, stigma and isolation.

It's essential that initiatives for dementia research care and support represent diverse lived experiences. There are 28,000 people in Canada living with young onset dementia. Young onset dementia affects people between the age of 18 to 64 and can bring a range of life changes. This must be included in the framework for dementia care.

The dementia experience calls attention to the need to address each circumstance within the broader life context, ensuring that support systems are adaptable and holistic.

I'd like to introduce Paul Robitaille. Paul will be speaking on behalf of our advisory panel. Paul is a caregiver that we have supported within our region through our services. Thank you.

**Mr. Paul Robitaille:** Thank you, Anna.

Good afternoon, honourable Chair and members of the standing committee. My name is Paul Robitaille. I'm here representing the Alzheimer Society of Peel's advisory panel for people with lived experience, which we call APPLE. So we're a group of individuals with direct experience with dementia, whether as caregivers or those diagnosed. Today I'm here on behalf of our panel to express our strong support for Bill 121 because we know first-hand the toll that dementia takes on those affected.

Dementia is one of the most devastating conditions. It's a progressive decline that slowly strips away a person's ability to think clearly, communicate and manage everyday tasks. Think about the simple task of tying our shoes. My mother, who worked for Peel police for 30 years, forgot how to tie her shoes, and ultimately how to even put on her shoes. She would often want to sleep with her shoes on because of the embarrassment and shame she would feel. This is not just a challenge for the individual. It creates a deeply isolating experience, leaving people disconnected from the world around them. Social circles often shrink, and many lose their autonomy as they become reliant on others for very basic needs.

But the impact of dementia does not stop with the person diagnosed. Families and caregivers just like mine are often thrust into caregiving roles without adequate preparation or support. I took a leave off work for three

months to be able to deal with the mental stress associated with this. I've seen it in my own community, people juggling full-time jobs, personal commitments and round-the-clock care for a loved one with dementia. It comes at a great cost—physical, emotional and financial—and many caregivers experience burnout and grief as they watch their loved one change, all while managing the stress and financial strain of caregiving.

According to the Alzheimer Society of Ontario, dementia is also a growing public health crisis. By 2031, over 300,000 Ontarians are expected to be living with dementia. Our health care system is not equipped to handle this surge and we cannot wait until 2031 to act. Many dementia patients occupy hospital beds because there aren't enough community supports, and long-term-care facilities are overwhelmed. The current model is simply unsustainable.

This is why Bill 121 is so important. It establishes a much-needed framework to address the urgent needs of people living with dementia and their families. The bill is ambitious, but it has to be, given the scale of the crisis that we face. Its focus on person-centred care, treating individuals with dementia with dignity and recognizing their preferences is critical and ensures that we don't just manage symptoms but provide the highest possible quality of life.

The bill also calls for better training—

**The Chair (Mr. Steve Clark):** You've got one minute remaining.

**Mr. Paul Robitaille:** —for health care workers and caregivers. Many front-line workers want to provide better care but lack the necessary training and resources. Bill 121 addresses this by advocating for comprehensive experiential training that will prepare workers and meet the complex needs of dementia patients with compassion and expertise.

One of the bill's most important aspects is its focus on equitable access. Right now, where you live in Ontario can determine the quality of dementia care you receive. That's simply unacceptable, and Bill 121 seeks to ensure consistent access to care.

Additionally, regular reporting on the state of dementia care, as outlined in the bill, is crucial for accountability.

In closing, Bill 121 is not just a legislative measure; it is a lifeline. It brings hope—hope that people living with dementia will receive the care they deserve and that caregivers will not be left to carry this burden alone.

On behalf of APPLE, we strongly urge you to support the passage of this bill so that we can build a future where every person and family affected by dementia can access the care, dignity and support they deserve. The Alzheimer Society of Peel and its advisory panel, APPLE, thank you for your time.

**The Chair (Mr. Steve Clark):** Thank you both.

We'll now move to our third and final presenter, the MINT Memory Clinic. Introduce yourself for Hansard and you may begin.

**Dr. Linda Lee:** Yes, I'm Linda Lee. I'm the executive director of MINT Memory Clinic, which is a not-for-profit organization dedicated to improving dementia care across Ontario. I want to thank MPP Smith for the invitation to

appear today and for tabling this very important piece of legislation, and I want to express my complete support for a provincial dementia care framework and appreciate that you are making it a reality with Bill 121.

By way of background, I should also add that I'm a care-of-the-elderly physician. I am the executive director for MINT but also the director for the Centre for Family Medicine MINT Memory Clinic and the Kitchener-Waterloo regional MINT Memory Clinic. I'm a Schlegel research chair in primary care for elders, and I'm an associate clinical professor with the department of family medicine at McMaster University.

Some background about my work: MINT Memory Clinics are an Ontario solution which integrates primary care into dementia diagnosis and care in a way that hasn't happened before. It seamlessly integrates primary care with specialist care and with community care so that individuals living with dementia and their family and care partners can now access timely, full-service, complete care that can be accessed within their own communities.

There are now more than 100 MINT Memory Clinics across Ontario and 22 MINT clinics across Canada in five provinces, so our Ontario solution is being adopted across Canada. We are helping to build health care system capacity for high-quality dementia care in primary care, reducing pressures on our limited number of specialists and giving people with dementia more time at home with their families.

We're also helping to address the human health care resource shortage by leveraging Ontario's primary care infrastructure that exists and making better use of primary care through standardized, nationally accredited training and enabling them to deliver the kind of care that people want and deserve. That includes a strong focus on training person-centred care, which is an objective of Bill 121.

There are a lot of challenges in dementia care right now. There is a backlog for access to specialists across our province that varies from months to well over a year wait time in many parts of our province. That backlog results in delayed diagnosis and treatment for individuals with dementia.

There was an Ontario study that showed that, within five years of diagnosis of dementia, half of people will not be alive at the end of five years. Only one quarter will be living in the community and half of those people will have transitioned into long-term care. This is a serious illness. It's a terminal illness. Early diagnosis and treatment are critical to changing this trajectory and helping people to live at home for longer with the best quality of life for as long as possible.

1520

Delayed diagnosis is now status quo. It results in individuals and families not receiving optimal care. That results in crisis, which results in emergency department visits, hospitalizations and early transition into long-term care. As many of you know, about 80% of people in long-term care have dementia, and the rising number of people with dementia in our communities will put even more pressure on our long-term-care system, which is already

short in capacity. So early diagnosis and treatment is important, and by identifying and managing this at early stages, which means it needs to be in primary care, and reducing the need for specialist referral by 90%—which is what MINT clinics have been proven to do in many studies; they've been shown to reduce the usual 100% referral rate, based on the province's own independent evaluation. The MINT clinics reduce that 100% referral rate down to less than 10%, so a 90% reduction in referral rates.

That does two things: First, it reduces the pressure on specialist wait-lists, streamlining only the most necessary, the most complex, so that the people who really need to see specialists can access that sooner; and, second, it allows individuals and families timely access to diagnosis and care in their own communities. For 90%, that will mean that it can be provided in the primary care setting; and for that 10%, leveraging our Ontario Telemedicine Network with the multitude of specialists that support the MINT clinics so that people can get the care they need in their own communities.

That's what we at MINT clinic have been focused on, but it's been led by those of us in the system who do this work voluntarily. It's important to codify MINT clinics in the province's dementia care strategy through the Bill 121 framework. By having a dementia care framework, Ontario has the opportunity to codify the partner-led aspects of the system that are working to address capacity issues and speed up diagnosis and care so innovations like MINT Memory Clinic can be part of a new standard of care across Ontario. It's not the only step needed, as funding for dementia care is lacking, but a framework is necessary as a first step to address this challenge.

**The Chair (Mr. Steve Clark):** Thank you very much for your presentation.

We'll move now to the round of questions. The independent member, you will begin with your four and a half minutes.

**Ms. Aislinn Clancy:** I'm so grateful. I love this part of our job, because we get to learn from the best experts. Thank you so much for sharing your story of what it's like as a caregiver.

I'm going start with Dr. Linda Lee. I live in Kitchener, so I got to visit your clinic, and it was fascinating. I think I've told a lot of people about it, and I just wonder if you could elaborate more. One of the things that struck me is how, when we build capacity and we work as a team—so, one, could you elaborate on the team model approach that you have, because I know we're having a shortage of primary care physicians, but you do a lot to bolster that and support the physician, but also a bit about expenses. I recall a lot of numbers about how it actually reduces the cost on our health care system dollar-wise. I think the emotional burden is the main area where we want to relieve pressure, and I'm sure it does that as well, but the data that struck me was a bit around the financial benefits of this model. Can you elaborate?

**Dr. Linda Lee:** Oh, absolutely. I can start with that. The MINT Memory Clinic has been extensively evaluated

by the province itself. In 2018, an independent provincial evaluation showed that MINT clinic care was associated with 50% less hospitalization costs, 50% less emergency department costs, 38% less overall health care system costs from time of diagnosis until death, and delay in transition into long-term care. This was the province's own evaluation.

There was a published health economic evaluation in BMJ Open just last spring that showed that there was \$51,500 net cost savings—that is inclusive of everything—to operate these clinics; \$51,500 less for every patient seen, and quality of life was improved. So it was extensively evaluated to show that we can, actually, deliver better care at lower cost.

With regard to the interprofessional team, MINT stands for multi-specialty interprofessional team, and that is the crux of the model, where we train nurses, social workers, pharmacists, occupational therapists, family physicians—whoever is on the team—so they now work together as a team to deliver the kind of full-service care for people, from the timely diagnosis and all the service and supports they might need, because dementia is really complex and the care needs to be individualized where the dyad is different from one person to the next. Some people need more services than others, so individualizing the care through the multidisciplinary team, it's cross-sectoral of all the people who need to be involved throughout the journey. That's what MINT does.

**Ms. Aislinn Clancy:** I guess one area that I'm concerned with as well is that there are parts of our province that have less access. It's great to have you here because I feel like you've already created a bit of a framework; you already have so much data and you've done this just because you knew it was the right thing to do in the work that you're providing. Thank you for being a leader and a trailblazer in this area.

Can you share a bit about how you can—I think of our northern communities and how there are a lot of limitations—

**The Chair (Mr. Steve Clark):** There's one minute remaining.

**Dr. Linda Lee:** The MINT clinics—most of them are in rural and remote areas. For example, Red Lake; it is the furthest north you can drive. It means that 90% of their people can get all the care they need locally with their MINT clinic team. The 10% who are most complex use virtual telemedicine to Toronto and to Thunder Bay.

People don't need to travel. It really increases equitable access, so people get the same level of high-quality care no matter where they live.

**Ms. Aislinn Clancy:** And you've established the capacity of these leaders that are sharing this expertise.

**Dr. Linda Lee:** Absolutely. Several hundred physicians do this work, and team members.

**Ms. Aislinn Clancy:** Thank you very much.

**Dr. Linda Lee:** Thank you.

**The Chair (Mr. Steve Clark):** We'll now move to the government. MPP Smith.

**Ms. Laura Smith:** Through you, Chair: First of all, I want to start by saying we're so pleased that we have so many professional individuals, including people who provide the care; I'm with you and I understand your journey. Every journey is different, but I just wanted to start by saying thank you to all.

Dementia is complex. That is quite a reality. I could literally spend an entire afternoon—I think both Minister Kusendova and I would love to pick each one of your brains for a very long time, but I'm going to start with discussions about early detection and intervention in cases where delaying the onset of dementia just by one year can make all the difference.

Ms. Studzinski, you talked about one of the tactics or things that you've discovered along the way that can make dementia more—the individual, the patient and their family members will be aware of the issue far before it happens. You talked about a retinal scan. I'm wondering if you could elaborate and give us a little more detail on that.

**Ms. Christa Studzinski:** Absolutely. I'm happy to do that, MPP Smith.

RetiSpec is a made-in-Ontario start-up company, and their technology is similar to when you go to the eye doctor, and they take a picture of your retina to look for glaucoma and—

**Ms. Laura Smith:** It's the exact same process?

**Ms. Christa Studzinski:** It's the exact same process. It doesn't require a new camera. It's a new filter that just goes into the device that's already deployed into the optometry clinic.

What the company has done is they've built out some machine-learning algorithms to analyze that data, and the output predicts who actually has dementia-related pathology in their brain.

**Ms. Laura Smith:** How is that done?

**Ms. Christa Studzinski:** In terms of the technology?

**Ms. Laura Smith:** Yes. How do you detect dementia in a retinal scan? What is evident in that retinal scan that shows?

**Ms. Christa Studzinski:** I'm not going to speak to the biology and the science of it, but essentially what it is is the retina is the window to the brain. There are cells in your retina that actually connect into the brain, and so the idea is that the pathology can make its way into the retina as well and be detected there.

**Ms. Laura Smith:** How early can you detect that?

**Ms. Christa Studzinski:** It's pretty well-established now that brain pathology actually starts well before people are diagnosed with dementia. There's something called mild cognitive impairment, and, in many instances, there are some signs of pathology even before a diagnosis of mild cognitive impairment.

Your brain is a magical, magical organ. You've got lots of different pathways there and it tends to find ways of working around problems. So when the pathology is there and the brain cells are dying, you don't necessarily see the impact of that right away. It takes a while for enough damage to occur that you can actually see the symptoms.

**Ms. Laura Smith:** Once again, I'm going out of the scope of my grade 10 or 11 science, but are we talking a decade? Are we talking five years? With the technology that you're looking at, where can we see that and how can we get to the issue faster?

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**Ms. Christa Studzinski:** Yes, that's a really great question. Actually, I was just talking to the company a few weeks ago, and one of the things that they would love to do is be able to say, "Hey, let's look at someone in their fifties and let's deploy this and test it as a screening tool, to see how early we can actually find some of this pathology in the retina," so that we can make sure that we're intervening and providing alternate strategies where people feel empowered to exercise and eat a healthy diet and take care of all the other things that can actually really promote a healthy brain and delay the onset of dementia.

**Ms. Laura Smith:** I'm going to ask you—and perhaps we'll get to Peel Alzheimer's, because I respect everyone who's here and I know everybody wants to hear more from all of you. But can you provide insight how delaying the onset of dementia would impact the health care system, particularly in terms of reducing the numbers of individuals who would require long-term care and hospitalization?

**Ms. Christa Studzinski:** I'm going to totally turn it over to Dr. Lee, if that's okay, because I feel like you're better positioned to be able to actually speak to this from a clinical perspective.

**Dr. Linda Lee:** Absolutely. I think the key is early diagnosis. The mild cognitive impairment stage affects, actually, about one in five people over age 65; it's common. Many of those people—some would say half to two thirds of them—will progress to dementia eventually. That's the window of opportunity where lifestyle interventions make a big difference. There have been many, many studies that show lifestyle does help, especially in these early stages, and there may be treatments—newer treatments, disease-modifying treatments—that are aimed at this stage.

The difference is between taking people who are—in that middle stage, people are functional, and it means they can continue to function. It means they can stay at work. They can keep doing the things that are important for them. So it's not taking them out of the workforce. And from a care partner perspective, it's having the person that's important to them maintaining their functioning and being able to do things that are meaningful.

I can't emphasize enough how important it is that we aim for early treatments, and that begins with diagnosis. If you don't have an early diagnosis, which is the gateway to service and supports, this doesn't happen. And the status quo right now is late diagnosis, where we can do much less.

**Ms. Laura Smith:** Mr. Chair, can I ask for time?

**The Chair (Mr. Steve Clark):** Sure: 1:35.

**Ms. Laura Smith:** I'm going to pass my time over to MPP Pierre.

**The Chair (Mr. Steve Clark):** MPP Pierre.

**Ms. Natalie Pierre:** Good afternoon. Thank you all for taking time out of your busy schedules to come and participate in the committee hearings today. It's much appreciated.

I have a couple of questions for Paul. First of all, I just admire your courage for coming forward and sharing your personal story. You talked a lot about the role that families play in caring for their loved ones and for individuals with dementia. You talked about emotional, financial and the physical burden of caregiving and how that can be overwhelming and you mentioned about taking time off work. So how important are family support programs such as those offered by our community partners in helping to alleviate some of this caregiving burden?

**Mr. Paul Robitaille:** I hate to sum it up in one word, but very—when you look at the financials and dig into that, a lot of workplaces, for example, may not allow certain people to take time off work to start the support. In our case, my sisters and myself, our mom went from retirement to starting to show signs within two years or so, and it just went very, very quickly. So you're scrambling very quickly to take time off and there are a lot of sacrifices we have to make.

So how important is it to have community support programs like that in place for our family, basically like a triage, almost? Extremely important, because we're just forging forward on our own. We're learning our things for the first time. We don't know—

**The Chair (Mr. Steve Clark):** Unfortunately, we're out of time for the government's first round. We're going to get another round of questions later.

We'll now move to the seven-and-a-half minutes for the official opposition. MPP Vaugeois.

**MPP Lise Vaugeois:** Thank you very much for being here. It's really a pleasure to hear what each of you has to say.

Just so you know, we're also in support of the bill, but I do have some questions and things I'd like to have clarified. Christa, you talked about a free five-minute test. Do you have an indication that that would be OHIP covered at this point?

**Ms. Christa Studzinski:** The intent of the company is actually to deploy this freely, so OHIP wouldn't actually have to pay. What we would need is then to make sure that there is a—so the test is like a green light, yellow light, red light. If it was a yellow light or a red light, we would just need to make sure that the coordinated and cohesiveness of the care pathway triggers some sort of follow-on action where the individual knows where to go, whether it's a MINT clinic, whether it's a local Alzheimer Society for cognitive screening or to an optometry clinic. This is where the coordinated and cohesiveness of the approach would really make sense, because every community is going to be different, and how do we make sure that we catch those people so that when they do do the test, they're not left at home panicking and afraid.

**MPP Lise Vaugeois:** So this is a test that's already been developed and they don't need to make a profit from it because it's already been developed through research—

**Ms. Christa Studzinski:** The company's intent is actually to deploy this freely, yes.

**MPP Lise Vaugeois:** Excellent. That's great to hear.

You mentioned banks, and I wasn't clear: How does a bank help to detect this?

**Ms. Christa Studzinski:** Well, so this was just me sort of trying to think outside of the box as well, right? But you can imagine someone who's going to the bank and trying to withdraw a large sum of money, it's a little bit atypical, and if we could equip those people to actually be able to sort of understand: Hey, what might be going on here, and how can I intervene in a way that's not clinical, obviously, but certainly in a way that sort of asks the right questions, where that person or that teller maybe feels empowered to sort of reach out to Alzheimer's or give the individual information about what they might want to consider doing.

**MPP Lise Vaugeois:** Okay—

**Ms. Christa Studzinski:** It takes a village, right? Yes, absolutely.

**MPP Lise Vaugeois:** It might make some people explosive.

And then, just quickly, RetiSpec: Is that something that would be happening automatically, and would the person, then—so a person doesn't have to get permission to have that part of the test done?

**Ms. Christa Studzinski:** That is a great question. I think it really depends on how we approach this. Is this something that's going to be paid for through the health care system? Is this something that's going to be out of pocket? I mean, hopefully not; the idea would be to make this accessible and equitable. You also need the individual's consent. You can't just run a test on them without them saying it's okay. But once the individual has given consent for that test, it's a matter of seconds. It doesn't take a very long time to administer.

**MPP Lise Vaugeois:** Thank you very much. I'm hoping to get to questions all down the line here.

The MINT Memory Clinic, not-for-profit—you've referred to some voluntary work. You said that you're in Red Lake. Now, I'm in northern Ontario, Thunder Bay–Superior North. We've got family health teams across the north. They're all on the verge of collapse. It is teamwork. It's fantastic. So I'm just wondering, how to finance—how do we bring in a MINT clinic into a system that's on the verge of collapse?

**Dr. Linda Lee:** The health care teams are funded—the allied health care professionals are funded through government because they're teams. What we do is, it's a super efficient model and it takes the hardest parts out of dementia care for the family physician. So we make it easy for them and we share care. It's been refined so that the levels of satisfaction with family physicians are very high. Patient and caregiver satisfaction—I think Health Quality Ontario helped to support a study; 96% of people would recommend the service.

So on all fronts, it makes it easier. We reduce the pressures on the family physicians by having the team well-trained to take those hard parts out. The satisfaction rate is very high. I think if it was from the province encouraging

that these be developed everywhere, we could leverage that infrastructure that's already in place.

**MPP Lise Vaugeois:** Right. Okay. So probably some additional cost, but maybe not, but it might balance itself out over the long run.

**Dr. Linda Lee:** It absolutely balances out because that was in the health economic evaluation, the net cost saving of \$51,500.

**MPP Lise Vaugeois:** Thank you. That's excellent.

So here I am; I am working down the line. I want to, first of all, thank you both for being here from the Alzheimer Society. From what I know of the Alzheimer Society in Thunder Bay, they do an incredible amount of work with very little money. I hope to see not-for-profit organizations actually see their funding increase so that there's not so much stress and perhaps not so much of a reliance on volunteers all the time, even though the volunteers are great also.

I noted the strain for you on the family, and one of our members had put forward a caregiver tax credit so that people who take time off from work to care for somebody who is ill are not penalized economically. Can you see a benefit to that?

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**Mr. Paul Robitaille:** Of course. I think anything helps. I think the challenge is, when you have work programs, you have to forgo a lot to be able to afford to stay back versus when you get a credit—of course that's going to help. So anything helps. We suggest more—absolutely. Everybody always wants more, especially with the mortgage rates increasing. There's a lot of pressures on families, where they have to work even double jobs now, so imagine that strain that people have. So, yes, that does certainly help, and we appreciate that very much.

**MPP Lise Vaugeois:** Thank you very much.

How am I doing for time?

**The Chair (Mr. Steve Clark):** You have one minute and 15 seconds.

**MPP Lise Vaugeois:** That's pretty good. Okay. I might have run out of questions—yes, go ahead.

**MPP Jill Andrew:** How much time do I have, Chair?

**The Chair (Mr. Steve Clark):** Fifty-eight seconds.

**MPP Jill Andrew:** I'll just start with a personal note, then, actually, to Paul: Thank you for sharing your story about mom and the three decades that she served as a first responder. Thank you for her work. My mom doesn't have Alzheimer's; she has neurosarcoidosis. While we were looking to figure out what this rare disease was, I stumbled upon, of course, many of your organizations, and I know the good work you all do.

I just want to express that I know and understand some of that emotional, mental, physical and economic stress that being a caregiver comes with. We love our parents, and we do what we got to do because they did it for us. I thank you for being here, and just to echo what my colleague said, we do need to recognize caregivers as integral parts—

**The Chair (Mr. Steve Clark):** Thank you, MPP Andrew. Thank you for your comments.

We'll now move to the second and final round of questioning for this panel. MPP Clancy, your four and a half minutes start now.

**Ms. Aislinn Clancy:** I'd like to pass it over to the Alzheimer Society, and I'll let you guys figure out—rock, paper, scissors—who goes first.

There was a \$10-million fund announced a couple of years back; it was announced again a few years later. I guess there's a little worry that some families who had to go through this without as much support were left behind. Can you share a little bit about what those supports would have meant, had you had them sooner?

**Ms. Niké Anna Myers:** Yes, definitely. I think part of the issue is just the awareness of the services and the program that we have. My understanding is that quite a bit of that funding went towards our behavioural supports initiative. But definitely within the community, it's more about access and having a range of programs, from counselling, education, not just for the care partner but also for the caregiver. That could be allied health care professionals, and that's where we look at also education, looking at funding for educating PSWs and other health care professionals as well.

**Ms. Aislinn Clancy:** Yes, I'm hearing that it's not just about the family physician. That's a big crux and big part of it, but how do we equip more people around that family physician to alleviate the pressure on them and to make sure there's a whole wraparound support—

**Ms. Niké Anna Myers:** Yes.

**Ms. Aislinn Clancy:** Thank you.

Another concern that comes up a lot with our seniors and our elderly folks is, again, the amount of hospital bed use. We see a lot of people end up in an emergency room without that prevention. We do have Bill 7 that tries to alleviate the stress of that by putting somebody in a care home that's far away from their family, and that can be a real tragedy. How do you see that from your perspective, Dr. Lee, where this model could maybe create a compassionate alternative to moving people from hospital, far away from family, and moving them into the wraparound model you're talking about?

**Dr. Linda Lee:** I think that's a really good point. I think right now our system is pretty reactive, and there just aren't enough long-term-care beds available for all the people that need long-term care. If we were to develop a model where we're proactive, where people are getting the services and supports they need early on so they don't run into the crisis events that result in hospitalization—and by that I mean, people with dementia also have other medical conditions, like heart failure, COPD, diabetes. You can imagine how much cognition is needed to give yourself insulin, to be able to manage puffers four times a day. People with dementia can't do that, so their health destabilizes. There was an Ontario study that showed that in people with dementia who present to an emergency department room, half of them get hospitalized because they're too sick to go home. When you have dementia, you have a five times greater risk of developing delirium, of which not all the time it recovers. About one in five people

will have permanent memory loss, so they no longer can go home. They end up in hospital, which are very expensive stays, which is not their fault. They're called ALC. They're waiting to transition into long-term care.

The solution is to work backwards, into primary care, into the community, and to build these services and supports so people can get the diagnosis early—

**The Chair (Mr. Steve Clark):** There is one minute remaining.

**Dr. Linda Lee:** —and can get the services they need to prevent that destabilization. Much of what we do is actually taking away medicines that worsen cognition and addressing the other conditions, like alcohol and sleep apnea, and things that we know can actually prevent a person from getting worse. These are the things that you need a multidisciplinary team to do.

**Ms. Aislinn Clancy:** I guess the worry is that because there's a shortage of primary care physicians—a lot of folks are without—they might end up in a walk-in clinic or something, and then emergency rooms, so we're left with those alternatives. Is that a factor in what you're seeing?

**Dr. Linda Lee:** Yes. Actually, in our Kitchener-Waterloo area, it serves the whole region, and we accept from walk-in clinics. So the population that doesn't have a family physician, we can still serve.

**Ms. Aislinn Clancy:** You get referrals from there?

**Dr. Linda Lee:** Yes.

**Ms. Aislinn Clancy:** How do you manage that without—do you have a big wait-list?

**Dr. Linda Lee:** Our regional memory clinic has a growing wait-list, and we need to manage that. We're hoping that with Bill 121 more funding—

**The Chair (Mr. Steve Clark):** Thank you, MPP Clancy. That ends this round.

We'll now turn to the government. MPP Pierre, did you want to continue your questions from the first round?

**Ms. Natalie Pierre:** Yes, thank you, Chair.

Paul, I'll come back to you. You got cut off in the last questioning. You were sharing some of the emotional and financial and physical burden of caregiving, I think it was, to your mom. I saw you nodding your head a lot during the last round of questions from MPP Clancy about preventative care.

I'm just wondering, in terms of the last question that I asked about family support programs offered by community partners and the community programs, if you could talk a little bit about your experience and what you found helpful.

**Mr. Paul Robitaille:** We found it very helpful that Alzheimer Society of Peel was right down the street from us. We were not concerned about proximity, but it just happened to be really convenient in a time where someone has got to take mom out to do that. Having these things just down the road is so important to us and the support that we've gotten from them.

What happens is you don't even know what they have yet. There's something happening. You notice it—leaving a car door open etc. And it's not just for my mom; I've



heard that from the community. So imagine when it goes from that to, all of a sudden, something faster and faster. Then you learn that there's this dementia scale. You learn about that a year down the way even though there are amazing resources within Alzheimer Society of Peel itself in Ontario and beyond.

We kind of have to forge our own in some ways and rely on the primary family physician. It's tough, because the burden almost goes on them. That's who we rely on. But then we get put into the community for other things. It seems like we're getting calls for all these different things—assessments galore. It's quite a bit. It's amazing stuff; it's just finding the right path for us that we understand, because it takes a lot of time. That's where it affects the families, because we're taking calls in and around all the other priorities we have. Plus, you look at dynamics of the family, where you're looking at, "Am I going to do it? Is my sister going to do it?" There's a lot of challenges that come up just from that too.

So, yes, if I'm answering your question correctly, having that support system—and we do value that for sure. I'm not sure if there's anything else you wanted me to elaborate on from that.

**Ms. Natalie Pierre:** How important do you think it is for Ontario to take action now through Bill 121 to ensure that our health care system is ready for these kinds of future challenges related to dementia care?

**Mr. Paul Robitaille:** It would make a world of a difference, for sure. It would have done that for us if we had it when we were going through this just not too long ago. And the people I've spoken with about this already, they're saying, "I wish we had this. It would just be wonders." When I say something, even what I did, they're like, "Oh, my gosh, can I tell you about everything?" I'm sure we probably can hear that with friends or family or neighbours about the same type of thing. But, yes, absolutely, if this was through before it got started, it would have made a world of a difference in our own situation and those who I know.

**Ms. Natalie Pierre:** Okay. Thank you.

I'll pass it over to Minister Kusendova-Bashta.

**The Chair (Mr. Steve Clark):** Minister.

**Hon. Natalia Kusendova-Bashta:** Thank you to all the presenters for being here. Many of you we've worked with throughout this entire process, so thank you for your leadership and your expertise. It was invaluable to MPP Smith and I.

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I wanted to start by asking Dr. Lee a question. First of all, I do agree with you that our system is reactive and not proactive, and it has been, historically, for decades. We can look no further than to how we fund health promotion and disease prevention, compared to how much we fund treatment. The difference is staggering in terms of how we budget and how little money we spend on health promotion. I think there is some work for us to do on that front.

I do want to thank you for developing this incredible model, which is really equipping our family physicians with the right tools they need to help diagnose patients

with dementia early on. I think it's really important, what you mentioned, that if this disease can be caught early on, there are a lot of disease-modifying factors that we can use to actually extend the quality of life of that individual. I think even some of us in this room may not know what those disease-modifiable factors are that we can each do to do some self-care for ourselves to actually lower our own risk, because our jobs are very stressful and stress is one of the causes of dementia—lack of sleep etc.

So can you speak to some of those disease-modifiable factors that people with early onset, but also all of us, could implement in our lives to lower our risk of developing dementia?

**Dr. Linda Lee:** Yes, there's much evidence for Mediterranean diet; exercise, particularly aerobic-type exercise; social networking; cognitive stimulation—generally doing things that are challenging to do and doing more of them; multiple areas of expertise, hobbies; getting seven to eight hours of restorative sleep; reducing alcohol intake; and good oral hygiene. Those are all things that are really important, that we should be doing anyway, but especially when people are starting to notice the very early symptoms that might be mild cognitive impairment. They're very motivated to take up some of these lifestyle interventions.

So detecting it early and being able to empower, as Christa rightly said, makes a huge difference.

**Hon. Natalia Kusendova-Bashta:** I think one of the ones that you didn't mention is hearing—getting your hearing checked, and if you're experiencing hearing loss, actually getting treatment for it.

But I did want to ask you about the study that was published in 2023. You used some disease progression probabilities to calculate the annual disease transition probabilities using the medical record data from your MINT Memory Clinics. I'm interested, if you can just tell us quickly—we only have a little time—about the transition into long-term-care homes and what your study demonstrated based on the data your clinic has acquired over the years.

**Dr. Linda Lee:** This would be the provincial evaluation that was independently done. It was using ICES-level data in Toronto, and they were able to show that the delayed transition of 5.8 months, as compared to people who didn't have access to MINT clinics—which I think, in context, is huge, because the cost of long-term care is, what, \$80,000 per year? I'm not aware of any other program that has shown this outcome in primary care, specific to dementia, so I think we can delay that transition.

**The Chair (Mr. Steve Clark):** There is one minute remaining.

**Dr. Linda Lee:** That is cost savings for the health care system. But most importantly, people can stay living in their own homes with their families and with the best quality of life in their communities. So I think that makes a difference.

**Hon. Natalia Kusendova-Bashta:** Just to be clear, patients who were in your clinic, based on the data that

came out—their transition into long-term care was delayed by six months as a result of all of your interventions.

**Dr. Linda Lee:** That's what the authors of that report concluded. It was delayed transition into long-term care by 5.8 months—so nearly half a year—when they have access to MINT clinic care as compared to those who didn't have access.

**Hon. Natalia Kusendova-Bashta:** That's incredible. What was the sample size?

**Dr. Linda Lee:** Oh, gosh, I'd have to look. It's on our website. The whole evaluation is on our website.

**Hon. Natalia Kusendova-Bashta:** But it was statistically significant?

**Dr. Linda Lee:** Oh, yes. Very much so.

**Hon. Natalia Kusendova-Bashta:** That's incredible. Thank you for all your hard work.

**Dr. Linda Lee:** Thank you.

**The Chair (Mr. Steve Clark):** We'll now move to the official opposition. MPP Andrew.

**MPP Jill Andrew:** The Minister of Long-Term Care rightfully said that stress can contribute to dementia. We know that stress is certainly a social determinant of health—your living conditions, your working conditions, your economic realities. I would also argue that being an underpaid or understaffed PSW, a nurse, also adds to your stress. I say this because I happen to know front-line health care workers who are doing the double shift of being a front-line health care worker—underpaid, understaffed, arguably disrespected—while looking after parents with dementia, with Alzheimer's, with various brain challenges.

My first question, as we support this bill—and I certainly support it as a first step, as a nod. We need a provincial strategy. We needed it six years ago, but it will be here soon. What is the importance of having front-line health care workers at the ready? How important is it for this government to properly fund, to pay a livable wage to our PSWs so they stay in the sector, to our nurses in long-term care, in home care, sectors that we know are starved? How important is that to the holistic care of folks with dementia and Alzheimer's? Dr. Lee, maybe?

**Dr. Linda Lee:** Yes, it's incredibly important. In terms of work satisfaction, adequate compensation is part of it. Part of it is meaningful work and having proper training. I certainly commend the idea of person-centred care in long-term care. I work in long-term care. I manage many, many people with advanced dementia in long-term care, and staff is everything. And having meaningful work, having proper training can greatly improve their satisfaction and retention, I would think. So I think that's really important.

**MPP Jill Andrew:** Thank you. I appreciate that, Dr. Lee.

I've also had a chance to speak with neuro-ophthalmologists, neurologists, neurosurgeons—of course, family doctors—and the truth of the matter is, all of you have spoken about early detection, early detection, early detection. Some 2.5 million Ontarians don't have access to primary care. They're saying this could raise to 4.4 million

by 2026. So the early detection of our primary care is eluding 2.5 million Ontarians.

Can you speak to the need for more primary care physicians as the centre of the provincial dementia and Alzheimer's strategy? Because, at the end of the day, we don't have enough doctors, and the many doctors I do speak to are buried under paperwork 19 hours a week or more; 40% of their time is spent doing paperwork or more. And, as a side note, the official opposition, we put forth an opposition day motion calling to support more doctors with more administrative staff, with interdisciplinary health care staff, and it was shot down and voted against. So can you express to us how important it is for our family doctors, these heroes, to be supported so that folks have them? How important is it having a family doctor for early detection? Anybody can answer, because you're all experts at this.

**Dr. Linda Lee:** Since I'm a care-of-the-elderly family physician, I can say, yes, it's really, really important. We need to work on training more primary care clinicians. That includes NPs and family physicians.

I think also equipping our current family physicians—which used to be 15,000 in Ontario; post-COVID, I'm not sure how many there are—to make this job easier for them. That's what MINT clinics do: They use the inter-professional health care providers to take the hard parts out. And that's what we need, to make the job easier for them as we train more physicians to do this work—and nurse practitioners—and enable that multidisciplinary approach.

**Ms. Christa Studzinski:** Maybe I could just also just weigh in a little bit—

**MPP Jill Andrew:** Please, please. Yes.

**Ms. Christa Studzinski:** —because, absolutely, I 100% agree with that. But there's also, thinking about the coordination and the cohesiveness—how can we leverage community organizations and allied services to help provide some of that support so that the family doctors can do their job better? And once we have that whole problem figured out, what happens once the disease-modifying therapies are here and we need to refer to a specialty care centre so that patients can get access to disease-modifying therapies that actually halt the disease?

So there's not just one solution here, and this is why the fact that this bill supports the coordinated and cohesiveness of this framework is really where we think it's going to be transformative.

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**MPP Jill Andrew:** Thank you for that.

What's my time?

**The Chair (Mr. Steve Clark):** One fifty.

**MPP Jill Andrew:** I can't express how important it is to have a framework, because the left hand needs to know what the right hand is doing, right?

I think, if I may just step ahead a bit, that framework, behavioural modifying drugs or therapies, we need to ensure that those are also equitably available. I know I came in a few minutes short, but I believe Anna, a respite care manager, was also speaking about the equity con-

sideration—health equity—and how important it is for us to have, whether it's culturally relevant care or whether it's recognizing the different socio-economic backgrounds that our patients and caregivers come from. So I definitely agree.

As I said earlier, it is a nod, it is a good step, it's important, it will help with organization, but at the end of the day, beds—we all love a bed; we all need beds. In Sunnybrook in my community, or just outside of my community, there were no beds for a woman in the community who had to go very far to get a bed. But beds don't take care of people, right? The PSWs do, the nurses do, the doctors do, the caregivers do.

In the short time I have, I just would like to give a shout-out to MPP Wayne Gates, frankly, who put forth this caregiver benefit, a small drop in the bucket to health caregivers with costs of food for their loved ones. We know that food and dementia and Alzheimer's—there are connections between our nutrition.

I want to say on the record that the Alzheimer Society of Ontario, Canadian Centre for Caregiving Excellence, Canadian Cancer Society, Community Living and Ontario Caregiver Coalition—

**The Chair (Mr. Steve Clark):** Thanks, MPP Andrew. Unfortunately, we're out of time.

I want to take this opportunity to thank the four of you for presenting today. I really appreciate the opportunity to come forward to the committee.

TORONTO MEMORY PROGRAM  
ONTARIO DEMENTIA CARE ALLIANCE  
EISAI CO., LTD.

**The Chair (Mr. Steve Clark):** I'm going to ask that the 4 o'clock—I'm going to do a little switcheroo—make their way to the mike: the Toronto Memory Program, Ontario Dementia Care Alliance and Eisai Co., Ltd.

Thank you, the four of you, for coming to present this afternoon on Bill 121. It's the same as the first group—I think you were here when we began: You'll each have seven minutes to make your presentation. I'll give you a time check with one minute left, and then we'll have two rounds of questions, split seven and a half minutes for the government, seven and a half minutes for the official opposition and four and a half minutes for the independent member.

I'll ask the Toronto Memory Program to begin first. If you want to introduce yourself for the purpose of Hansard, and your seven minutes will begin right now. Go ahead.

**Dr. Sharon Cohen:** Thank you, Chair. It's a pleasure to be here. My name is Dr. Sharon Cohen. I'm a behavioural neurologist and Alzheimer's expert. Thank you to Minister Kusendova-Bashta for the invitation and to MPP Smith. I very much appreciate being here. I totally support Bill 121. I want to help provide some clarity, as I've worked in the Alzheimer's space and related dementias for 30 years, both in clinical practice and as a clinical trialist aiming to

move the field forward with new and better treatments and early detection.

What is dementia? We've been spending a whole day talking about dementia, and I get the feeling that sometimes we're talking about different things. Dementia is not a disease diagnosis; it is a syndrome. It means that someone can no longer function independently because of problems with memory or thinking.

What is the cause? When you think someone has dementia, the very next question any health care practitioner should be asking is: "Why?" Is this a head injury, a stroke, a brain tumour? Is it Alzheimer's disease? There are many causes—many other than what I've mentioned.

The reality is, as we get older, we're all at risk for a very common disease called Alzheimer's disease, and this is the commonest cause of dementia in Canada, as around the world, although there are many other causes.

Let me just clarify a little bit about Alzheimer's disease and what the patient journey and trajectory is. Individuals start developing changes in their brain—accumulation of abnormal proteins, amyloid being the earliest—about 20 years before symptoms. So that means if somebody is developing Alzheimer's symptoms in their seventies, they have the brain changes in their fifties.

That's a scary thought, but it's also a very hopeful thought. We have a huge window of opportunity, 15 to 20 years, to prevent that person, if we can identify the early changes, before they even have symptoms. That's what we do with cancer medicine; we screen people. That's what we do for other diseases. We now finally have tools—and I'll get to that—so that we can detect this disease even before symptoms.

But as you accumulate toxic proteins in your brain, in Alzheimer's disease, after many years, as you heard Christa describe, brain cells can no longer compensate. You start to get symptoms. An individual recognizes something is not right with their thinking and memory. And if I, as a clinician, do a brief memory test, I can see that there is a problem. However, that person may be still shopping, banking, driving, working, having a vibrant life with family, socializing, home, hobbies. That person has the mild cognitive impairment stage of Alzheimer's disease.

Now, there are other degenerative diseases of the brain: Parkinson's disease dementia, frontotemporal degeneration. You heard about neurosarcoidosis, a very rare form. These have progressive courses that can go through a mild cognitive impairment stage, and then, gradually, as more brain cells are injured, you end up with a mild dementia phase where, "I can't drive anymore, but I can still do some other things. Maybe I can still shop. Maybe I can still cook."

And as you get to the moderate stage, now, more and more autonomy is lost. More and more things have to be given up and taken over by others. So it's really at the moderate and then the severe dementia stage where there are drastic losses of autonomy, of independence, escalation in burden for family members who are now providing hands-on care, helping with toileting, feeding, bathing.

In the mild dementia phase, most people say, “I don’t love being forgetful, but I can manage.” Quality of life is still pretty good, and studies have demonstrated that’s often the case in the mild stage. What we want to do is prevent those later stages. We’d love to prevent the whole thing, absolutely, but baby steps here. Can we keep people at early, either pre-symptomatic stages, mild cognitive impairment where they’re still fully functioning, or the mild dementia stage where quality of life is not too bad, care costs are not that bad?

Once you get to moderate and severe stage, that’s where you get the acute hospitalizations, the emergency room visits, the escalation in long-term bed needs, and the breakdown, not just of patients, but of family members: physical and mental breakdown; backache; burnout—all kinds of problems; being struck by their loved one who doesn’t recognize them. These are horrific problems that differ from one person to the next. Yes, there’s a lot of heterogeneity in the symptoms of a disease like Alzheimer’s disease, but the commonality is that people are suffering.

The individuals with the disease, they are not happily dementing, as some of us would like to think. They are anxious, depressed, paranoid. They are losing control of everything that they used to do on their own. Their families are suffering, not always recognized or appreciated by the one they’re trying to provide care for, often accused of stealing. You know, “Mom’s now accusing me, looking after her, of stealing her watch, her clothes, her money.”

So many sad stories. As a treating neurologist, every day—except for today, where I took a day off because it was so important to come here and support this bill, and I thank you for that, but it’s with the permission of my patients, and I’ll catch up with them shortly—there’s a heartbreak story here, and all these stories are important.

Many of you have shared stories, and I appreciate them, and I have my own, but I won’t burden you with them other than to say both of my parents died of Alzheimer’s. I kept them at home with me because I couldn’t put them into the bureaucratic and cold institutionalization process—not easy. There’s nothing easy about this, but there is hope, and when we talk about early diagnosis—

**The Chair (Mr. Steve Clark):** There’s one minute remaining.

**Dr. Sharon Cohen:** —we are talking about not just identifying dementia, we’re talking about identifying cognitive impairment and what is the cause. We have specific tests—I said I’d get back to this. The retinal scan: I’m actually the principal investigator on that Canadian study, so if you have questions about RetiSpec and the eye scan, I can answer those. But there are blood-based biomarkers coming. We have scans approved to detect amyloid in the brain that detect the disease change before symptoms. And we have spinal tap and analyzing spinal fluid that can detect the change.

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I know my time’s up, but the treatments that are coming are so important because they will be indicated initially for that early stage of disease. We can’t let our patients miss a

treatment opportunity, so we’ve got to let them move forward and fast-track them to treatment.

**The Chair (Mr. Steve Clark):** Thank you, Dr. Cohen.

We’ll now move to the Ontario Dementia Care Alliance, if you want to introduce yourself for the purpose of Hansard and give your presentation.

**Dr. Jenny Ingram:** Thank you. I’m Dr. Jenny Ingram. I’m a geriatrician hailing from Peterborough, Ontario, and I’m the chairperson of the Ontario Dementia Care Alliance. MPP Clark, MPP France Gélinas and members of the Standing Committee on Social Policy, I appreciate so much the opportunity to present to you today and to come here to support Bill 121, Improving Dementia Care in Ontario Act.

As I said, my name is Jenny Ingram. I’m a specialist in geriatric medicine, but my life has been spent as a community leader who has been at the forefront of developing and training nurse practitioner-led geriatric multidisciplinary teams. There are 12 of them scattered across Central East that are supported by geriatric medicine specialists. Those 12 locations service the very complex patients that are needed to be seen in our rural, far-flung communities.

I also am an investigator at a research site similar to the one that Dr. Cohen comes from. This is called Kawartha Centre. So I’m intimately involved in the exciting evolution of antibody treatments for Alzheimer’s disease.

I’m a strong advocate of the pivotal role primary care teams can and should have in dementia care. This has been an ongoing area of study, and I’ve worked hard to assist primary care teams at the grassroots level to learn how to do dementia analysis and diagnosis. I’ve dedicated my career to giving voice to people with dementia and their families and friends and supporters. I also might say, I’ve been loud and proud as an advocate for aging at home and living life fully with dementia at home, wherever that home might be.

But I stand here today—I don’t actually; I sit here today—not as those credentials might suggest, but as the chair of the Ontario Dementia Care Alliance, a non-partisan group with stakeholders from many disciplines, backgrounds and a common focus on improving dementia care.

I want to thank the MPPs from Thornhill and Mississauga Centre for jointly introducing this important legislation last year. But, in particular, I read MPP Smith’s revelations of her two family members with dementia. This was echoed by MPP John Fraser, and it was a reminder to us all of just how ubiquitous this condition is and how many people, families, care partners are embroiled in the issues without much in the way of guidance, support or additional personnel day to day.

And lest you think that this disease only impacts older Ontarians, think again. In Canada, 83% of care partners for people living with dementia are between the ages of 23 and 65. That demographic forms the backbone of Ontario’s workforce.

The 250,000 to 300,000 Ontarians with dementia today are expected to triple by 2050. Each of these folks is supported by somewhere between three and six to 10

helpers to keep them managing while at home, if at all possible. So the one million persons with dementia in 2050 really translates to four to five million Ontarians having to support this disease.

Despite the staggering scale of dementia in Ontario, care planning and provision is disjointed, ineffective and disorganized. It has three ministries: health, long-term care, seniors and accessibility; multiple agencies, including Ontario Health regional offices and Ontario health teams; multiple community agencies: the VON, the Alzheimer Society, St. Eliz, community care—we go on and on. And the responsibility for organizing and orchestrating these competing options is left squarely on the backs of the families, because who is in charge?

It is often said, “When dementia care is everyone’s responsibility, it is no one’s responsibility.” In that regard, we’ve left Ontarians on their own to find housing that might backfill for the challenges with dementia in the early phases, or to pay for help until you qualify for long-term care. Even then it takes a crisis to get you through the door, and if a crisis isn’t good enough, a crisis plus going to the hospital will get you through the door.

This is not how any of us would envision health care delivery and it is not a reality that we want to pursue in the future. This bill is the answer to changing that.

**The Chair (Mr. Steve Clark):** There is one minute remaining.

**Dr. Jenny Ingram:** I appreciate the framework designed to support improved access to dementia care that this bill supports and the legislative requirement of the Ministry of Colleges and Universities to introduce dementia-specific training, but it must go beyond PSWs and embrace all the professionals who also need to know and learn about dementia.

The Ontario Dementia Care Alliance has put forward, before the last budget, this Promoting Access to Dementia Care in Ontario, which dovetails with this legislation and includes an Ontario dementia care strategy, interdisciplinary care models, improved and timely diagnosis and expanded home care supports from diagnosis to death, as part of what we need to see.

**The Chair (Mr. Steve Clark):** Thank you, Doctor. Thank you for your presentation.

**Dr. Jenny Ingram:** I look forward to supporting this further. It’s a wonderful bill

**The Chair (Mr. Steve Clark):** We will now move to our final presenter in this 4 o’clock slot, Eisai Ltd. You can introduce yourself for the purpose of Hansard and you can begin.

**Ms. Laveena Kamboj:** Excellent, thank you. I wanted to first thank Minister Kusendova and MPP Smith for the opportunity to speak today.

My name is Laveena Kamboj and I am here in my capacity as a senior director for value access and policy, a team at Eisai Canada, to express our enthusiastic support for Bill 121.

Eisai is a global pharmaceutical company. We’re headquartered in Tokyo, Japan, and we have a strong presence in Ontario through our Mississauga office. Our company

specializes in two key therapeutic areas, and that is neurology and oncology, with a commitment to advancing research and development.

At Eisai, we are driven by our core philosophy, which we call human health care, or HHC, and our mission revolves around supporting all Canadians by creating solutions in areas where significant medical challenges and treatment gaps persist. We put patients and their families first, not just through innovation but also by ensuring equitable access to treatments.

Over the course of this year, and as an example of our HHC mission, Eisai has collaborated with health charities across Canada. Those include the Alzheimer societies, Dementia Network Calgary, CAMH, the MINT Memory Clinics and people with lived experience, including those living with early Alzheimer’s disease, or AD, and their care partners. We’ve collaborated with advocates and primary care networks to co-learn about the difficulties faced in navigating the health care system and the day-to-day challenges of people living with early AD. We uncovered many insights of how the health care system could better meet the needs of patients and their families, which we published in three separate reports.

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Some of the key learnings from our dialogues with those living with early AD and their partners include the following—and I just want to mention that we met with 63 people living with disease and their care partners. Some of those learnings include that living with early AD impacts all aspects of life. Persons living with early AD want to focus attention on what they can do versus what they cannot do, and on the belief that life with AD, while different, can still be deeply meaningful.

The current lack of a treatment pathway to diagnosis can be a traumatic process for patients and their care partners, and can create intense frustration and despair, due to the unpredictability of the care pathway and a recurrent dismissal of their concerns. In contrast, for those families that have experienced a more streamlined care pathway—and that’s usually through a hard-fought referral to a memory clinic—they felt more reassured and confident about their treatment journey.

There’s little information shared with people impacted by early AD by their health care practitioners about what to expect, available resources, methods of treatment, or how to manage their condition in the early days. People living with early AD desire more time in the earlier stages of the disease, before more severe cognitive and functional impacts develop. This allows them to spend more quality time with their families, doing things they value and that bring them joy. This may be realized through earlier diagnosis and/or new therapies that slow disease progression.

Additionally, we have also been meeting with the government to discuss the importance of system readiness as it relates to Alzheimer’s disease, ensuring the health care system is prepared to support the growing capacity of Alzheimer’s patients and the arrival of new disease-modifying treatments.

We believe that we represent a significant source of hope for patients dealing with challenging conditions like early Alzheimer's disease through our treatment Leqembi, which is positioned to bring about a significant advancement in the care of Alzheimer's patients. This innovative therapy can alter the prognosis and timeline of the disease, ultimately improving patient care. However, the efficacy of cutting-edge treatments like Leqembi hinges not only on their development but also on the readiness of the health care system to accommodate them.

Despite medical advances, a critical obstacle exists: the issues of timely diagnosis. Too often, patients presenting with early symptoms of Alzheimer's disease are missed, their cognitive decline attributed to the natural process of aging. This oversight is exacerbated by the constraints faced by general practitioners who lack the time and resources to conduct comprehensive cognitive impairment assessments.

The goals of Bill 121 perfectly align with Eisai's mission to foster access to quality care for Alzheimer's patients. The bill seeks to improve care for those affected by dementia by mandating the development of a provincial framework by the Minister of Health. The legislation's focus on regular reporting on the state of dementia care ensures greater transparency and government accountability. This framework represents a much-needed structured approach to addressing the growing dementia population in Ontario. Dementia patients and their caregivers face significant challenges, and the legislation helps address gaps in access to necessary services and care.

A key aspect of the bill is its recognition of the essential role of caregivers—

**The Chair (Mr. Steve Clark):** There is one minute remaining.

**Ms. Laveena Kamboj:**—and the need for better support systems to alleviate their burden. Families and caregivers of those with Alzheimer's and other dementias need enhanced services, which this act aims to deliver. Passing Bill 121 would represent a significant milestone in the province's journey towards a more inclusive health care system.

We stand ready to offer our continued support to ensure the successful passage and implementation of this important legislation. Eisai looks forward to working with the Ontario government to foster innovation and ensure better outcomes for those living with Alzheimer's disease.

**The Chair (Mr. Steve Clark):** Thank you very much for your presentation, all of you.

We'll now begin with the government's seven-and-a-half-minute round. MPP Pang, you can go first.

**Mr. Billy Pang:** Mr. Chair, through you, my first question is for Laveena, and then the rest can put your thoughts in. When I get older and am losing my hair—and also memory now. When we are supporting patients with dementia, families play an integral role, as you mentioned earlier, in the care of individuals, but the emotional, financial, physical burden for a caregiver can be overwhelming. Could you elaborate more on the type of support services available for families, such as counsel-

ling, education, respite care, and how these services contribute to the well-being of the patients and their caregiver?

**Ms. Laveena Kamboj:** The phase of dementia and Alzheimer's disease that we focus on is the early phase. Really, if we start to identify people at that stage, it would actually help in terms of preventing or at least helping—the other longer-term things can be dealt with in a better way.

Some of the things that we found is that for the caregivers, even in the mild stage, there's actually quite a bit of burden. You think, why is that? There isn't a lot of functional impairment of the patient at that stage. What is happening, though, is they're managing their spouse or their partner in terms of reminding them of things that they need to do. They've got to navigate the financial aspects of their life. People still want to be functional, and they try to do this the best they can, but the care partner is the one that is doing most of that managing and also navigating the health care system.

Looking for help within the health care system—it's the care partner that is trying to find that help, and what they're finding is in that early stage of the disease, there isn't much help being offered. If you are fortunate enough to be at the memory clinic that Dr. Cohen and Dr. Ingram are at, there's a lot more education that is provided to patients, but not a lot of patients get that opportunity. Many do not get to a memory clinic, and so they're left figuring out the system on their own with their caregivers.

**Mr. Billy Pang:** Yes, I believe that dealing with that at an early stage is best, but there's a stigma there that—they're very reluctant to deal with the reality.

**Dr. Sharon Cohen:** Maybe I can comment on stigma, and you're absolutely right to highlight early detection. There is huge stigma, particularly around Alzheimer's disease. This is a disease that many still feel a palpable sense of doom when they hear the word and that it's a diagnosis worse than death, worse than cancer. I have a patient who got cancer after a diagnosis of Alzheimer's and said, "Hey, I won the lottery, I'm going to die of cancer, not AD." This is how much people fear this disease.

Stigma is not just in the individual; it's in society, and it's in our health care system. Patients may realize, or individuals may realize their memory is slipping. They're fearful of going to the doctor and being told, "You can't drive anymore," or being told that they've got a diagnosis like Alzheimer's and, "There's nothing we can offer you." That's a terrible thing. We want people to come forward and say, "Maybe this is Alzheimer's, what can you do for me?" Not, "I don't want to see you because I'm too scared to get the diagnosis and to lose my autonomy."

And then, on the part of health care practitioners, a huge amount of education is needed because, as Laveena mentioned, people often approach and re-approach many times to try and get a diagnosis, and they are sent away saying, "Oh, you're just anxious," or, "What do you expect for being 70." Things are trivialized and minimized, and our health care providers, both specialists and in primary care,

often don't want to deal with this disease because they don't feel they have enough to offer.

Times have to change. We do have things to offer, and you alluded to, "Could it make a difference, even in the absence of a pharmacologic therapy?" Yes, education, a specific diagnosis, understanding the path, planning ahead. We don't need people to go out in their slippers and freeze to death in the winter. That happens every year in Toronto. Wandering alert bracelets, helping people plan their powers of attorney, get their estate in order: These are things people can participate in at mild stages, at the MCI stage, or even mild stage of dementia, rather than having everything taken over and losing their voice completely at a later stage.

So early diagnosis allows people the autonomy, the dignity, to plan their future.

**Mr. Billy Pang:** Thank you.

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**The Chair (Mr. Steve Clark):** MPP Smith.

**Ms. Laura Smith:** Through you, Chair, I want to thank everyone for being here today. We always appreciate all of our partners in the work that's being done.

We talked about the role of early diagnosis. Just for information's sake, my mother was diagnosed at a 22 on the MMSE scale, which is the mini-mental state exam, which is used commonly. That's something that I think most of the professionals here at the table are aware of. That is a mild level, which allowed her to stay at home longer. It wasn't until other circumstances that she went down that slippery slope.

But getting into that issue where the individual is at a mild to moderate stage, could you talk about what evidence there is for person-centred care and improving the quality of life for those early stages and, specifically, what that training would involve and how that would improve that individual's quality of life?

**Dr. Sharon Cohen:** There are many, many aspects to person-centred care, but at the heart of it is letting the patient, the person with the problem, have a voice. What I see often amongst health care practitioners is they talk to the family. I try to refocus: "You're my patient. At whatever level, you can tell me what's bothering you or how you feel. I'm going to listen to you." I also want to hear from other family members.

**The Chair (Mr. Steve Clark):** There's one minute remaining.

**Dr. Sharon Cohen:** But, yes, it really starts with giving the person a voice, understanding a little bit about their background, their hopes, their values, their interests, and then you go from there at whatever stage of disease.

**Ms. Laura Smith:** Respecting the patient or the loved one or the—

**Dr. Sharon Cohen:** Exactly. Respect, dignity—these are huge, important words.

**Ms. Laura Smith:** And letting them make the choices.

**Dr. Sharon Cohen:** Exactly.

**Ms. Laura Smith:** Thank you.

Time?

**The Chair (Mr. Steve Clark):** Thirty-eight seconds.

**Ms. Laura Smith:** I'm going to ask one last question. Very quickly: What will happen if we do nothing?

**Dr. Sharon Cohen:** We are already going backwards in terms of rising numbers and fewer—you've heard about not enough family practitioners and not enough resources for existing family practitioners and PSWs. That's true. I don't think you've heard enough about not enough specialists. The number of neurologists who are dementia experts as opposed to migraine and epilepsy and stroke experts is a very small handful. Luckily, we're joined by colleagues in geriatric medicine—

**The Chair (Mr. Steve Clark):** Thanks, Doctor. That's the government's first section over.

We'll now move to the official opposition. MPP Andrew.

**MPP Jill Andrew:** Thank you very much, Dr. Cohen, for saying that last piece on specialists. I've heard that directly from one of the very few neuro-ophthalmologists we have here in Ontario.

I wanted to go back to Dr. Ingram and the numbers you expressed, where you said the 315,000 people with dementia now—we're looking at a million by 2050; we're looking at four or five million caregivers supporting those with Alzheimer's. I was told by the retired teachers' association of Ontario when I went to speak with them that there is an abysmal lack of geriatricians—that there aren't enough of them. I'm wondering if you can expand on that, because I'm assuming, without them, we cannot get many of these tests done.

**Dr. Jenny Ingram:** The three specialty areas that handle a lot of individuals with dementia when referred to by primary care would involve geriatricians and geriatric medicine, geriatric psychiatry and neurology. So we all have a role to play in this.

Geriatric medicine by and large has done quite a bit in the area of dementia and frailty and complexity. They, in many countries, are the mainstay of in-hospital hospitalist care; of pre-care before you go to surgery with hip replacements. When I was recently in St. Mike's, I found that there was a geriatrician on their trauma team to try to orchestrate the care specifically for people who had trauma that are over the age of 65.

So there are roles needing to be filled by all of these people, but geriatric medicine has really been a mainstay in the community. We have gone, since 2010 to the present, from me to 12 geriatricians as a result of our geriatric teams that have developed.

I took some liberties looking at the Provincial Geriatrics Leadership Ontario presentation, and in 2023 there were 32,000 geriatrician visits, 17,000 neurology visits and 12,000 geri-site visits, so there is a lot of patient need out there being shared by the three specialties.

Currently, the funding for geriatric medicine is really at the bottom of the barrel and is a very big problem. I'm actually in a position of leadership at the OMA in that regard as well, but don't get me going.

**MPP Jill Andrew:** Thank you for that.

What is my time, Chair?

**The Chair (Mr. Steve Clark):** A little over four minutes.

**MPP Jill Andrew:** Thank you for this. First of all, I was pleasantly surprised to hear this come from my time with the retired teachers' association of Ontario and I am glad that I was able to share today.

Moving to Dr. Cohen: I appreciate how you said it is not about a diagnosis. There is a series of symptoms and there is a series of things that can be pieced together with various tests—the MoCA test, whichever test—to come to a synopsis of what folks may be dealing with.

I want to talk about housing. I'm trying to articulate my question and my thoughts here. These stages—beginning, middle, acute: Can you talk about how long each stage may be, recognizing that no one person's journey is the same as another? I'm wondering what we can do in terms of housing accessibility to ensure that folks with dementia or Alzheimer's at any age can age in place as best they can. I'm thinking particularly about a seniors' home safety grant, which we as the official opposition have been advocating for, and other things to ensure that we have the universal design so that folks can age in place. I wanted to hear your thoughts on this.

**Dr. Sharon Cohen:** Thank you for the question. It's a complicated one but I'll give it a stab, no problem at all.

As you rightly pointed out, there are stages along the continuum of a disease like Alzheimer's disease or other neurodegenerative diseases. In the early stages people are able to manage in their own home. At the dementia stage—once you get past the pre-clinical, that's no symptoms, changes in the brain—the mild cognitive impairment stage, where I might not just be living at home but travelling, shopping, working, banking; okay, that's fine.

Once I transition to the dementia stage, most people still in the early dementia stage—or mild dementia stage, I should say—are able to live at home with a little bit of help. If they are without any family, if they're living alone, then things might be precarious. You may need someone to check that they're taking their medications regularly or their medicines or blister package. There is some risk but not extreme. It is in the moderate and severe stages where people really can't live unsupervised or without some hands-on care.

But most people want to stay in their own home, so that hands-on care comes either from family members, from helpful neighbours, from hired personal support workers or government-provided personal support workers. When you can patch together enough time for care—

**The Chair (Mr. Steve Clark):** There's one minute remaining.

**Dr. Sharon Cohen:** —then you can remain in your own home. Otherwise you need to transition to a more supportive environment, and long-term-care beds are not always the best place, so this is a problem.

**MPP Jill Andrew:** What should we be doing to make housing more accessible—a more universal design at the blueprint stage? What do we do to help people stay at home longer or age in place?

**Dr. Sharon Cohen:** Sure. Dr. Ingram is going to take that.

**Dr. Jenny Ingram:** There is a lot of evidence that assisted living in cluster care, which has been the subject of great scrutiny by the Auditor General, is one of the models of care that allows low-income individuals a supported existence.

If I may, I'll just put in a pitch that the idea that home-based services have to be allocated in big chunks of time, once only in the day, is completely irrelevant to someone with dementia who needs it throughout the day.

1640

**The Chair (Mr. Steve Clark):** Thanks, Doctor. So we've finished this round with the official opposition. They'll get another round in a bit.

The independent member, MPP Clancy: You have four and a half minutes.

**Ms. Aislinn Clancy:** Thank you very much. I do appreciate the expertise here. I learn lots and I admire all the work you've done in your career to be good advocates and caregivers with your many hats. It sounds like you wear many hats.

One thing I wanted to draw attention to, and I wonder if I can ask Dr. Ingram to speak to it—there's voices missing today. This bill specifically names PSWs as people who need more training, and yet there are no delegates today from the PSW sector. And to me, the PSWs I've met are newcomers, racialized women, people living on a low income, often, sometimes single parents—precarious work. Can you tell me, Dr. Ingram, in your work, how do you include PSW voices, voices of folks with dementia—we are missing those here today as well. What do you say to that?

**Dr. Jenny Ingram:** I have a number of things to say about PSWs, because they are really the workhorse of our care system in health care, and they don't get subsidized until late on in the disease. Most families who are successful at caring for someone at home negotiate for private PSW supports that they accumulate from all sorts of different places.

In terms of training, the training for PSWs—yes, it needs to be much more formalized and recognized, especially around dementia care, but I would just caution you that they are not the only ones within the health care system who need to learn about dementia; even your surgeons and anesthesiologists, even the ward clerks etc. need to know about this.

In terms of PSW retention, in the game teams where I worked, we had three PSWs who were part of an over-arching team that worked with the most difficult patients and would go in with a BSO nurse and teach the PSWs on the scene how to manage a particular behaviour. And by having a team-based PSW who was in an educative role—they did not leave their job; they loved that job, they were paid full-time and they did well—the impact on the bedside care or the household care was dramatic.

And, finally, I would say that I just interviewed, on the weekend, a family. I'm cataloguing families who have done unique things in home care and kept people with



dementia at home. And each of the family members spoke to me about their Lydia, who was a PSW, and they said, from beginning to end, she provided them with the consistency and the trusting involvement that allowed them to listen to her and believe that she understood. And she's a mature woman who's got lots of experience in dementia care, and that person was the person from whom they learned when it was time to start putting a tracker in the woman's shoes, when it was time to start other things. They're very important.

**The Chair (Mr. Steve Clark):** There's one minute remaining.

**Ms. Aislinn Clancy:** So it sounds like, in your line of work, listening to PSWs and having their voice there is a game-changer.

**Dr. Jenny Ingram:** Huge, huge.

**Ms. Aislinn Clancy:** I just want to say, as a former social worker, that I'm hearing from you that they're also a key part of the team. I have a friend in long-term care, an allied health professional, and we need to, I assume, pay folks well and then also give them that respect.

**Dr. Jenny Ingram:** And put them in a team.

**Ms. Aislinn Clancy:** Yes. I always refer to the phrase, "Not about us without us," and that's—at least, if our PSWs aren't here with us today, I'm glad you could share a little bit about what it means, and I hope that we can continue to seek out that voice directly.

**The Chair (Mr. Steve Clark):** We'll now move to the government. MPP Grewal.

**Mr. Hardeep Singh Grewal:** I'd like to thank all three organizations for taking the time today to come out and speak to Bill 121. Thank you for taking the time out.

My question is going to be for Sharon Cohen from the Toronto Memory Program. I just wanted to talk about what kind of interventions or detection methods are most effective in achieving this delay and what kind of role public awareness campaigns could play in promoting early diagnostics. What can we do, not only as a government, to help engage the community and make sure they know about all of the things to help them gain awareness on early-onset dementia? And how do we ensure that they're giving their seniors, their parents, the right care and pushing them towards the right segments and the right programs?

**Dr. Sharon Cohen:** Thank you so much for your question. I really am a prevention kind of person, so I appreciate what you're saying.

I didn't say much about my program. We are a community-based, multidisciplinary memory clinic with family docs, geriatricians and geriatric psychiatrists working alongside neurologists, so we're pretty unique that way—not in a hospital. I do a lot of going out into the community, the greater Toronto area, speaking to different community groups, whether it's retired seniors or retired business professionals, discussing early detection, early prevention and what's coming in the treatment pipeline.

We offer cognitive screening. We offer genetic testing, which could be looking for a risk gene for Alzheimer's disease. We absorb the cost. We do this free of charge. We

destigmatize the disease. We say what the options might be if you have risk factors or, if there's cognitive impairment, what are the next steps.

There are so many things that can be done to get to a precise diagnosis. The retinal scan is not yet Health Canada approved, but that will put screening in the hands of optometrists, and allow them in the community to be partners in screening specifically for Alzheimer's disease, not any dementia. There are many things. But routinely in our clinic, every day, we do spinal taps as an outpatient procedure, collect precious spinal fluid and send it off to a lab to look for Alzheimer's proteins. We can make a definitive diagnosis.

And we know that without biomarkers, we are wrong 50% of the time when we say someone has Alzheimer's; they actually don't, if you look for the biology. Can you imagine telling someone they have cancer without doing a tissue diagnosis, or radiating someone for cancer treatment, giving them toxic chemotherapy, and they didn't end up having cancer? That would be malpractice. We do this every day with Alzheimer's. We call it "probable Alzheimer's," no biologic confirmation.

There's a huge amount that can be done. It starts with public awareness, public awareness campaigns, education. And communities are very open to this. If I don't show up with my Genomadix Cube to do the risk gene testing, people are saying, "Dr. Cohen, you didn't bring that. We wanted that." People are lining up for this. Community is waiting.

**Mr. Hardeep Singh Grewal:** Thank you so much. I'd like to share the rest of my time with my colleague, Minister Kusendova-Bashta.

**The Chair (Mr. Steve Clark):** Minister?

**Hon. Natalia Kusendova-Bashta:** How much time do I have?

**The Chair (Mr. Steve Clark):** You have just a little over four minutes.

**Hon. Natalia Kusendova-Bashta:** Wonderful.

Thank you to all of our wonderful presenters for being here today, and thank you for being partners in putting this bill forward. Your expertise and knowledge is very much appreciated.

Just to MPP Clancy's comments on not having a PSW representative here today: As you guys know, this committee was oversubscribed. We've had great turnout, and we're very, very proud of the work that we've both done to engage such a large number of stakeholders.

There was, in fact, IBT College, which applied but was unable to be heard today. I hope they do send us their submission in writing. It is a college which is training PSWs, and they have developed a very interesting program through virtual reality. MPP Smith and I were able to experience the virtual reality, and when you put those glasses on, you actually experience the symptoms of those living with dementia. So those PSWs, as they are training, can actually immerse themselves virtually into that world of those people living with dementia. It was quite an eye-opening experience for us to have access to that technology, and I'm glad to see that colleges across Ontario are

stepping up and really thinking outside of the box and being innovative about how we train PSWs for the realities of working with seniors living with dementia.

I did want to ask a question to the Ontario Dementia Care Alliance. Thank you so much for being here today. I do have your report here on promoting access to dementia care in Ontario. On page 16, you talk specifically about a recommendation for long-term care. As the Minister of Long-Term Care, obviously, I'm very, very interested in hearing what you have to say.

**Dr. Jenny Ingram:** Oh, dear. I'd better read it quick.

1650

**Hon. Natalia Kusendova-Bashta:** Recommendation number 5: If you could speak to that a little bit and just share with me why this is something so important to those 17 experts that are a part of your panel.

**Dr. Jenny Ingram:** This was an amalgam. Both of us were on—I'm speaking on behalf of many people who have spoken before who are part of the Ontario Dementia Care Alliance, and really, the idea of having a way to deal with dementia that is individualized and specific to the people in long-term care is part of what we're talking about, so that you can modify their behaviours, modify their care plan.

I'll just note that we have a system, just generally in health care, that tries to fit people into what we want to provide, and what I think we're getting at is to assess the person and what they need and try to create a system around them.

Just as an aside, I'm going to tell you my favourite quip about long-term care. I have a patient—

**The Chair (Mr. Steve Clark):** There's one minute remaining.

**Dr. Jenny Ingram:** —who moved into long-term care early on after arriving in Peterborough, and his daughter wanted him to be able to walk, as he always wanted to walk, but it was not possible in the long-term care. She arranged for him to be able to have a golf buddy who, during the six years that he was in long-term care, took that man out of the long-term-care facility five to seven days a week to play golf.

Now, as he deteriorated, he played less golf and did more watching, and in the winters they played pool. But that was his long-term-care existence: It was to go out of the facility and have somebody who worked with him, doing what he needed to do, which was walk, walk, walk, walk, walk, and he walked the 18 holes throughout most of those six years.

So when this talks about flexibility and—

**The Chair (Mr. Steve Clark):** Doctor, unfortunately, we're finished with the government's round. I want to thank you for your answer.

We'll now move to the official opposition. MPP Vaugeois.

**MPP Lise Vaugeois:** I had an example, also, of a couple of people living fully, probably at an early-to-middle stage. I met them at the Alzheimer Society. One is still playing double bass; he'd always played double bass, and he was still able to keep playing with the band. And another: I was at a dinner, and she said, "Hi. I have Alz-

heimer's, and I don't want to hide." It was just very good and very positive to see both of those people.

But I did want to now—you were talking about various tests and so on. Can I get in line? There must be a million people in line who want to be in line right now for those tests, to find out. So I hope that what you do proliferates, so that there's no shortage of being able to access that.

In the summary of recommendations—I looked at this too—you talk about the Beers list of medications. Can you tell us about that?

**Dr. Jenny Ingram:** The Beers list of medications are medications that are commonly used—things that you might recognize even over the counter, such as Graval—that have a propensity to lower your memory chemicals within your brain. The list is very extensive, and most of the medications that we take for granted have a negative impact on brain chemicals in some minor-to-major way. Of course, it's a balancing act—you can't just remove them, often—but to keep track of them and to minimize them is a goal of any good clinician.

We had pharmacists on the Ontario Dementia Care Alliance who felt they could play a pivotal role in assisting primary care and other individuals in finding those medications, interactions and problem areas.

**MPP Lise Vaugeois:** Now, you're in the—

**Ms. Laveena Kamboj:** Pharmaceutical?

**MPP Lise Vaugeois:** Thank you—the pharmaceutical business. Is that something that resonates with you? I guess what I'm thinking is that we all hear these stories of a family that says, "I just felt I had to take them off everything because they were deteriorating because of the medication," or they believed that. As you say, if you take everything away without controls, then you create other problems.

**Dr. Jenny Ingram:** I will just say that in the research that we do with the pharmaceuticals, we need a minimum of problematic medications on board in order to be entered into some of these research trials. Having said that, as a general overture to people out in the community, managing your medications appropriately and working with your physician and your pharmacist to use appropriate and targeted medications is always the way to go; stopping them just because you feel it's good for Friday is not a good idea.

Even in the medical profession, we have areas where we don't serve our dementia patients very well. Often, people get onto a cascade of medications where you're giving an antidote to a side effect for something that started as a mild headache but ended up as a tremor. These kinds of cascades are well known in medicine. That's what most of us in the dementia care world do as second nature.

**MPP Lise Vaugeois:** Just as a follow-up to that: In general practice, are those contraindications well known?

**Dr. Jenny Ingram:** I'm going to make a comment about general practice in that I've spent a lot of time—20 years—working in primary care training the nurses, and we have nurses and Alzheimer Society workers in primary care offering memory assessments to primary care physicians. It's not enough; we need the family health

team to have subsidized positions for dementia-specific individuals who can work through these problematic issues and help the primary care physician to nip it in the bud. After they get to us, somewhere downstream, it's often later than we would like.

**MPP Lise Vaugeois:** Thank you.

How am I doing?

**The Chair (Mr. Steve Clark):** You're at 2:45.

**Dr. Sharon Cohen:** Do you mind if I just add a comment to that?

**MPP Lise Vaugeois:** Please.

**Dr. Sharon Cohen:** One has to recognize that somebody may be managing their medicines very appropriately and they may be appropriate medications—and let's hope the family doctor and the specialist who've all been providing medications are doing so prudently. However, you reach a point, if you have a disease like Alzheimer's disease, where you may forget to take your medicines or you may double or triple take them because, "I'm not sure if I took it and I better take my"—so somebody who has thyroid disease and has been very well managed, or diabetes and has been euglycemic because their diabetes medicine was right for them, all of a sudden becomes hypothyroid or hyperglycemic and things cascade. Part of working up somebody who's on a slippery slope here and something has changed is figuring out, did something change in the medicines or is this just their Alzheimer's now escalating because the underlying disease is expressing itself?

Any skilled practitioner would be accustomed to looking at medications very carefully. I would say, in specialist care, we pay more attention to this, but that's not to say that a good family doc doesn't also pay attention to the medications. But really knowing what's going on in the home and whether the patient's taking them properly is a whole other situation that is under-recognized. Also, the well-meaning family members, they now double—I've seen all kinds of mistakes being made when someone else takes over your medications and doesn't really know what the intention was. So lots of eyes on the situation needed.

**MPP Lise Vaugeois:** Right. Thank you.

I think I probably have a minute or so?

**The Chair (Mr. Steve Clark):** You've got just over a minute, yes. Just a little over.

**MPP Lise Vaugeois:** First of all, I'm not France Gélinas, but I'm subbing in for her. You mentioned her earlier.

**Dr. Jenny Ingram:** Oh, that was the subcommittee earlier—the Vice-Chair.

**MPP Lise Vaugeois:** Right. Actually, you mentioned the nurse practitioner-led geriatric teams, and that's partly why I thought of France, because she has had a lot to do with helping to develop the nurse practitioner-led clinics, but not necessarily specifically for geriatrics. Can you talk a little bit more about that, please?

**Dr. Jenny Ingram:** This started in 2010 in Central East. It came as a result of an aging-at-home strategy where I think there were 12 of us pitching various bits and pieces of the health care system we wanted to fix, and none of us got any financial remuneration because of the ALC problem

in the hospital. Everybody on the phone call got quite annoyed and said, "Please, you have to help us." So with a year—

**The Chair (Mr. Steve Clark):** Thanks, Doctor.

**Dr. Jenny Ingram:** Oh, that's it.

**The Chair (Mr. Steve Clark):** Unfortunately, that's the end of the time.

I will go to MPP Clancy for her final four and a half minutes in this round.

1700

**Ms. Aislinn Clancy:** Oh, I get the whole thing. Okay, good.

Sorry, I'm going to go back to Dr. Ingram. You mentioned that you're part of the OMA, advocating on behalf of your profession, and you mentioned funding. I know you said, "I could go on and on," but maybe you could go on for a little bit: Talk about how we could better fund geriatric care.

**Dr. Jenny Ingram:** As part of the ODCA, first of all, specialists need recognition as requiring team-based care as well. There seems to be a disconnect that somehow specialists can do it all without a team, but we would never hire a surgeon without having surgeries available. However, the numbers of geriatric medicine specialists in Ontario, both needed and predicted to be needed, needs to escalate dramatically. I think we're around 230 max at the present time.

We have a crazy funding system that supports us 18 months after we've done our first billing, and so we basically don't get the benefit of this until much later. There is great dichotomy between the university teaching centres and those of us, like me, who are out in the community. We can't be supported on a fee-for-service basis. Most of us in dementia care cannot see, like my skin colleagues who see 100 a day and my cardiology colleagues who see 50 a day—we see between three and 10 a day. And if you get a really messy situation, fee for service is very impractical. It is our hope that the government, seeing the expansion of dementia by tripling, would view that the pool of resources spent and focused on specialist care would also expand, but that hasn't been in the planning at this point from the Ministry of Health.

**Ms. Aislinn Clancy:** Just speaking about doctors, I find that there's a lot of gaps and inequities among different specializations and doctors that obviously—

**Dr. Jenny Ingram:** We're together.

**Ms. Aislinn Clancy:** —is impacting how many people go into the profession, and it's a whole HR conversation in and of itself.

**Dr. Sharon Cohen:** Neurologists are probably the poorest paid.

**Dr. Jenny Ingram:** Even worse.

**Dr. Sharon Cohen:** Our situation is the worst. So you have to really be a very dedicated, passionate person who's an optimist to be in dementia care and be a behavioural neurologist. That's partly why there are so few of us. It's just not a sexy area of neurology. That will change. Once we have disease-modifying therapies, we'll have more individuals, just like with stroke care or other areas of

neurology—they'll become more interesting. MS: Now we've got 20 disease modifiers; when I was training, we didn't have any.

But what I want to say is that my practice, which is in the community, has provided a framework that is very replicable and we're very successful. As Dr. Ingram said or alluded to, most memory clinics in the community are loss leaders. That's why most behavioural neurologists work in ivory towers in the university, where they're supported that way. But we don't want people going to hospitals and university clinics—

**The Chair (Mr. Steve Clark):** Final minute.

**Dr. Sharon Cohen:**—we want them to come for outpatient care. That's where dementia care should be: in the community.

So our model is to have a specialist-led clinic; in our case, it's me, a behavioural neurologist as the medical director. I have neurologists, as I mentioned before. I have family practitioners working with us; care-of-the-elderly specialists, so people who have gone through the program, like Dr. Lee. We have, actually, a MINT geriatrics, care-of-the-elderly specialist working with us. We have a geriatrician working with us, a geriatric psychiatrist, and we have clinic assistants and research assistants. So we're all communicating, we're all sharing common information, and this is how it works the best.

**Ms. Aislinn Clancy:** Yes. But I'm hearing from you that we need a bit of a focus on the HR side of things. We've been focusing on PSW pay equity and attention, retention and recruitment. But it sounds like you're also seeing, from a specialist lens, that the retention and recruitment and pay equity is a big issue in your field.

**Dr. Jenny Ingram:** Even at the team level, there have been no enhancements—

**The Chair (Mr. Steve Clark):** Thanks, MPP Clancy. Unfortunately, this ends our time today.

I want to thank the four of you for attending the committee public hearings. We appreciate your involvement in the bill.

RHYTHMIC REHAB INC.

ELI LILLY CANADA INC.

MUSIC THERAPY ASSOCIATION  
OF ONTARIO

**The Chair (Mr. Steve Clark):** I'd ask now that we welcome, as we say goodbye to the 4 o'clock presenters—we have three final presenters for the rest of the day. I'm going to ask Rhythmic Rehab Inc., Eli Lilly Canada Inc. and the Music Therapy Association of Ontario to come forward and take a seat.

While we're getting settled, there's always a bit of time between a delegation leaving and one beginning, so I'll just give you the boilerplate comment that I've made. Each of you will have seven minutes to make your presentation before the committee. I'll give you a time check with one minute remaining, and then we'll start a rotation of 39 minutes between the government, the official opposition

and the independent member. So that will be seven and a half minutes for the government, seven and a half minutes for the official opposition and four and a half minutes for the independent member. So there will be two rounds of questions.

The first presenter is from Rhythmic Rehab Inc. I just ask you to introduce yourself at the start of your presentation for the purposes of Hansard, for our official records. Your seven-minute presentation begins now. Welcome.

**Ms. Kaitlyn Aquino:** Honourable members of the Standing Committee on Social Policy, my name is Kaitlyn Aquino, and I am the owner of Rhythmic Rehab Inc. I am honoured to be here today. I am a certified neurologic music therapist, the owner of Rhythmic Rehab Inc., the treasurer for the Music Therapy Association of Ontario, and a caregiver to loved ones living with dementia.

It is a privilege to address you regarding Bill 121, Improving Dementia Care in Ontario Act. On behalf of myself and music therapists working around the province to support the lives of individuals and their families living with dementia, I want to express my strong support for this bill's aim to improve dementia care.

As a music therapist, I have worked with individuals living with dementia in long-term-care homes, hospitals, day programs and in the community. I completed my education at the University of Toronto, obtaining a bachelor of music and a master of music in the applied music and health sciences. The process to become a certified music therapist includes the successful completion of a bachelor and/or a master of music therapy program, 1,000 hours of clinical internship supervised by highly experienced professionals, an exam by the Certification Board for Music Therapists and ongoing professional development to ensure that therapists are practising at the highest standard of care.

Through this extensive training, music therapists are uniquely qualified to use music safely and ethically to support cognitive, emotional, physical, social and spiritual needs. Music therapy is often associated with music wellness and entertainment, and while these initiatives support enjoyment and leisure, they are not a replacement for the evidence-based therapeutic benefits that music therapy offers.

I am here today to advocate for the inclusion of music therapy in person-centred dementia care. Person-centred care recognizes that individuals have unique values, personal history and personality, and that each person has an equal right to dignity and respect and to participate fully in their environment. As a music therapist, I am constantly asked, "What is the best music for music therapy?" My answer is always, "Client preferred is best." This is because music therapists use music to support personally relevant and meaningful goals. The more meaningful, the more engaged, the more the brain changes.

Neuroscience research shows us that music engages the whole brain, and in individuals living with dementia, music engages parts of the brain that are preserved, even when memory, language and cognition begin to fade. Playing personally relevant and meaningful music for individuals

living with dementia triggers emotions and memories, which can encourage engagement, conversation and connection. For individuals living with dementia, music is a powerful tool that can be harnessed to help them remember important times in their lives with their loved ones, supporting the very nature of person-centred care: that we each have unique values, histories and experiences, and that when nurtured in dementia care come through.

Music has the power to evoke emotional responses, alter our mood and elicit physiological changes. These effects are amplified when a music therapist creates a personalized intervention to address a specific need; for example, reducing personal expressions brought on by agitation, anxiety, depression and other symptoms of dementia.

1710

As dementia progresses, individuals often lose the ability to communicate verbally. I have worked with individuals who rarely, if at all, speak, and who begin to sing when a familiar song is played. A familiar song can help trigger automatic speech due to the strong associations of melody and text that are stored in our long-term memory, highlighting the importance of individualized therapeutic interventions in person-centered dementia care. Music, more specifically music therapy, transcends verbal communication. It fosters genuine human connection and helps to create spaces for meaningful interaction.

With a vibrant, multicultural population, a growing number of Ontarians in long-term care communicate in languages other than English and French. These residents often become isolated, having limited opportunities for social connection and interaction. Music therapists can help foster a connection in these residents, bridging a gap that language cannot, by engaging with music of different cultures, ensuring that every Ontarian has equal access to dementia care.

Music therapists work in a variety of clinical settings, from hospitals to long-term care and community-based practices. As part of the interdisciplinary care team, music therapists work collaboratively with personal support workers to deliver care. It is my hope that the training framework for personal support workers would include basic education about music therapy and its purpose to ensure that personal support workers feel equipped with the knowledge to recognize individuals who might benefit from music therapy.

I would also like to recognize the impact of the Canadian Music Therapy Fund. This fund has a long history of working to create access to music therapy programs in long-term care, providing critical financial support to music therapists working with individuals living with dementia. The Canadian Music Therapy Fund acts as a model for the expansion of services, highlighting the importance of strategic investment, which aligns with Bill 121's mission: that every Ontarian has access to quality dementia care.

I entered this profession because of the profound impact that music therapy can have on individuals living with dementia—my own two grandmothers, past and present.

Music therapy has the power to foster connection and cultivate a sense of self in individuals living with dementia. I have experienced this both as a music therapist and as a caregiver for my loved ones.

**The Chair (Mr. Steve Clark):** You have one minute remaining.

**Ms. Kaitlyn Aquino:** With music therapy currently recommended in Canada's national dementia strategy, I urge the committee to consider the inclusion of music therapy in person-centered dementia care. Including music therapy within the framework of Bill 121 would establish Ontario as a leader in the field of dementia care. I also urge the committee to consider the addition of music therapy to personal support worker training, as integrating this knowledge would enhance the quality of care and ensure that more individuals can access and benefit from this essential service.

I want to thank the committee for your time and consideration. With your support of Bill 121 and the inclusion of music therapy in person-centered dementia care, we can cultivate an environment that supports the unique needs and values of individuals living with dementia, ensuring everyone has access to quality dementia care.

**The Chair (Mr. Steve Clark):** Thank you very much for your presentation.

We'll now move to Eli Lilly Canada Inc.—if you can introduce yourself for the purposes of Hansard at the beginning of your presentation. Your seven minutes begin now.

**Mr. Kenneth Custer:** Wonderful. Mesdames et messieurs, I'm very pleased to appear today in my capacity as president and general manager of Eli Lilly Canada to address the Standing Committee on Social Policy on Bill 121, Improving Dementia Care in Ontario Act, 2024.

Eli Lilly and Co. is a global leader in innovative medicines that address unmet medical needs and improve the lives of millions of people around the world. I represent Lilly's Canadian affiliate, which was founded in 1938, following our collaboration with Dr. Frederick Banting and Charles Best of the University of Toronto, producing the world's first insulin at scale. We're headquartered in Toronto still today and have more than 350 employees across the country, the majority of whom are based in Ontario. Last December, we acquired Point Biopharma, a Toronto-based biotech, which adds an additional 70 Canadian employees to our roster.

In addition to appearing as a representative of Lilly Canada, I am here today as a person, an individual, one who is passionate about the science of the brain and that has a vested interest in finding treatments for neurological and psychiatric disorders. I grew up in a household affected by mental illness, an experience that led me to pursue a PhD in neuroscience. Since then, I've watched my father lose the ability to walk due to a devastating neuropathy, and I've watched my wife's family navigate a dementia diagnosis and, ultimately, the loss of a loved one, something that plausibly puts my wife and two daughters at higher risk.

Lilly's commitment to advancing the science of the brain and discovering breakthrough medicines is why I chose to work here 16 years ago. At Lilly, we've dedicated more than 35 years to advancing the science of Alzheimer's disease.

While there's much more to understand about its complex pathology, we've learned a tremendous amount. With new tools, we can better diagnose patients and rule out individuals who have other forms of dementia. We also have a more complete understanding of the role of amyloid plaques in Alzheimer's, which can appear decades before patients display recognizable symptoms but ultimately drive the neuronal damage that robs patients of their ability to remember, to think, to speak and to care for themselves. With this better understanding, we've been able to develop more accurate diagnostics and more optimized therapeutics, which I believe will make a difference.

The provincial framework supporting improved access to dementia care that Bill 121 will compel the government to create is much needed, and I applaud the members of the committee for undertaking this work.

Bill 121 is focused on person-centred dementia care. For people living with Alzheimer's disease, any improvements that treatment can make to how they are feeling, or in their ability to engage in daily tasks, can provide much-needed hope and encouragement. Despite this, health care systems are at present set-up to only diagnose and treat Alzheimer's disease after the symptoms become too impossible to ignore and when therapeutic approaches may be less effective.

Bill 121's requirement that consistent and equitable access be facilitated across Ontario is commendable. We strongly support a health care implementation that does not have levels of service that vary by postal code or demographic, and it is encouraging to see Ontario wants to get this right.

Bill 121 stipulates that the provincial framework take into consideration existing frameworks, strategies and best practices. While currently available treatment options and methods of care remain vitally important, therapeutic approaches for Alzheimer's diseases are evolving dramatically, offering fresh hope to individuals, caregivers and clinicians. These amyloid-targeting therapies offer a more proactive approach to the treatment of Alzheimer's disease by targeting the underlying causes. The aim is to change the course of disease progression, limiting the damage, keeping people living healthier, more independent and living longer lives, ultimately reducing their burden on family, friends and caregivers.

Lilly is proud to be advancing the science of Alzheimer's disease, but we know that we cannot do it alone. We are deeply committed to partnering with the Alzheimer's community to discover and deliver innovative diagnostic and therapeutic solutions that can pave the way for a better future for people living with Alzheimer's disease and their loved ones.

I would like to present three recommendations for your consideration today. I bring these recommendations forward to committee based not only on Lilly's own develop-

ment work pursuing disease-modifying treatments, but also the extensive engagement we've undertaken with stakeholders across the Alzheimer's disease ecosystem in Canada and in Ontario specifically to understand the potential obstacles and barriers to delivering effective end-to-end patient care in this new therapeutic area.

Over the last two years, we've engaged in hundreds of meetings with patient groups, dementia centres, health care practitioners and patients. We've heard from them that getting a diagnosis is challenging, and they often lack clarity about what they're supposed to do after they receive one.

Our first recommendation is that this bill support the creation and permanent funding of an entity like Cancer Care Ontario, which currently exists for oncology, to establish a predictable and stable diagnostic and treatment pathway that provides equitable, consistent and timely access to care for Alzheimer's disease and dementia patients and their families across all points of their journey.

One of the phrases we've taken to using at Lilly is, "Time is brain." As you may know, while the first generation of this emerging class of disease-modifying treatments slow the progression of Alzheimer's disease, they are unable to restore brain function that has already been lost. The swift identification of eligible patients is therefore extremely important. For this reason, our second recommendation is that this bill support an investment in the diagnostics infrastructure that will be required to identify appropriate patients before they pass through the window of eligibility and may no longer be helped by this new class of medicines.

Our third recommendation is that we believe Bill 121 should be updated to include the use of disease-modifying treatments for Alzheimer's disease as soon as possible once those medicines are available for use in Canada. We have seen the Premier speak recently about the need to increase the speed with which new innovative medicines reach Canadians, and we believe that this new therapeutic class, which addresses an area for which there has previously not been hope, is a prime candidate for acceleration.

Thank you for your time. I'm happy to take your questions.

**The Chair (Mr. Steve Clark):** Thanks very much for your presentation. I'll just ask you to say your name into the record for the purpose of Hansard.

**Mr. Kenneth Custer:** Apologies. Kenneth Custer.

1720

**The Chair (Mr. Steve Clark):** Thank you.

We'll now move to the third presenter in this 5 o'clock slot, the Music Therapy Association of Ontario. If you want to introduce yourself and your title, your seven-minute presentation can begin now.

**Ms. Steffi Friyia:** Honourable members of the Standing Committee on Social Policy, my name is Steffi Friyia, and I am honoured to be here today as both the acting president and vice-president of the Music Therapy Association of Ontario, as well as a music therapist with over 10 years of experience. I genuinely appreciate the opportunity to address you regarding Bill 121, Improving De-

mentia Care in Ontario Act. On behalf of MTAO and its members, I wish to express our strong support for this bill's aim to enhance dementia care in Ontario. We believe that music therapy plays a critical role in the person-centred care model proposed in this legislation.

For over a decade, I've had the privilege of working with people affected by dementia across a variety of settings, including long-term-care homes and hospitals. In these roles I have witnessed first-hand how music therapy can profoundly improve the quality of life for these individuals. I hold a bachelor of music therapy from Wilfred Laurier University and a master's in music and health sciences from the University of Toronto. My own work is rooted in evidence-based practice and rigorous training. As a credentialed music therapist I have completed the intensive training required to become a certified music therapist, a designation granted by the Canadian Association of Music Therapists. This includes a 1,000-hour clinical internship, supervised practise with experienced professionals and ongoing professional development to ensure our skills remain at the forefront of the therapeutic practice. The comprehensive training equips us to design and deliver personalized interventions that target cognitive, emotional and physical outcomes, ensuring the highest standard of care.

The Music Therapy Association of Ontario represents over 150 certified music therapists across Ontario. Our members are committed to using music in targeted therapeutic ways to address the diverse needs of individuals across various populations. It is crucial to distinguish here between music therapy and music wellness. While music wellness activities are valuable for leisure and enjoyment, they do not offer the same clinical therapeutic benefits as music therapy. Certified music therapists are specifically trained to use music strategically to address cognitive, emotional, physical and social needs.

Neuroscientific research shows that music engages parts of the brain that remain intact even when memory, language and cognition deteriorate. For many individuals living with dementia, familiar music can trigger memories and emotions, creating a bridge to their past. This aspect of music therapy is essential as it aligns perfectly with the person-centred care model that Bill 121 promotes. By focusing on the individual's potential for connection, we can significantly enhance the quality of life, allowing them to engage more meaningfully with their caregivers and loved ones.

Music therapy goes beyond using music for enjoyment. It facilitates meaningful interactions when verbal communication becomes limited. It has been shown to reduce agitation, anxiety, depression and other behavioural and psychological symptoms of dementia. For instance, I have worked with clients who, despite having difficulty verbalizing their feelings, could express joy or comfort through music. This non-verbal communication is invaluable in building trust and connection.

As part of a holistic approach, music therapists work collaboratively with the broader care team, including personal support workers. We address the evolving needs of

individuals as dementia progresses, creating interventions tailored to each person's unique journey. We hope the committee will consider including music therapy as a module within the training framework for PSWs. By understanding music therapy's potential, PSWs can be empowered to recognize and refer to a certified music therapist when a resident might benefit from therapeutic music interventions, especially when managing agitation or distress, where music therapy has proven to have a calming and stabilizing effect.

Furthermore, I'd like to highlight the long-standing impact of the Canadian Music Therapy Fund in long-term-care homes. This fund provides crucial financial support to music therapists working with persons living with dementia, ensuring access to specialized care in underfunded areas. The CMTF serves as a strong model for expanding music therapy services across Ontario, illustrating the significant benefits of strategic investment in this vital area.

By including music therapy within the framework of Bill 121, Ontario will be positioning itself as a leader in dementia care. Recognizing the power of music to unlock communication, maintain dignity and foster a sense of identity for those living with dementia would represent a significant step forward.

I urge the committee to not only consider the inclusion of music therapy as part of the person-centred care model, but also explore the potential to incorporate it into PSW training. This integration would enhance the quality of care provided to individuals living with dementia, ensuring that more people can benefit from this effective intervention.

In closing, I want to thank you for your time and consideration. Your support of Bill 121 and the inclusion of music therapy in dementia care can make a meaningful difference in the lives of many Ontarians. Together, we can foster an environment that values and supports the unique needs of individuals living with dementia, ensuring they receive the compassionate, comprehensive care that they deserve.

Thank you very much.

**The Chair (Mr. Steve Clark):** Thank you to all of you for your presentations.

We'll now begin the questioning. We'll start with the official opposition: seven and a half minutes, MPP Andrew.

**MPP Jill Andrew:** Thank you very much to Kaitlyn, Kenneth and Steffi for your presentations this evening. I do just want to say that after I finish this round, I have to leave because I've got to get back to my community of St. Paul's for a meeting.

But that said, I want to thank you all for bringing the A in STEM to today's conversations. This is something that I've been discussing with many of our theatre, visual arts, music, dance educators: that we need government, when they're talking about education, curriculum and even health care, as we've seen through the pandemic, to recognize that A. And let's talk about STEAM as opposed to STEM all the time, so I thank you for that.

As you were talking, I was thinking about my visceral reaction to Fleetwood Mac's Everywhere, or Kool and the Gang's Joanna. But that said, thank you for making the distinction between music wellness and music therapy. I think that's a very important piece to say.

So if I can ask Kaitlyn, specifically: Can you tell me how many clients or how many families or communities you are able to serve currently with Rhythmic Rehab Inc.? Are these services OHIP-covered? Are these services at cost? I'm certainly supportive of music therapy, of arts therapy. I've heard from doctors. I've heard from community members. I want to know more about your structure and if you're getting any support.

**Ms. Kaitlyn Aquino:** Yes, definitely. Music therapy is currently not an OHIP-covered service, so families, individuals do have to pay out of pocket. That's a big barrier to access care. Through Rhythmic Rehab, I am a new company. I serve in-home. So I currently see about 15 different families in-home.

In addition to that, you'll find that many music therapists do contract work with other businesses. So one of my other affiliations is with MIYA Creative Care. They are a business that brings music therapy to long-term-care homes. So, currently, I'm at a long-term-care home in Mississauga with 600 residents. I am the only music therapist for 600 residents, and I am there two days of the week. And this isn't unique to me; many music therapists face this problem where there are limited hours that they are offered to go into the home and you have to make these really difficult decisions of—essentially, everyone in this home could benefit from it, but who's going to get it? A big barrier to services is just the cost and not having that financial support.

**MPP Jill Andrew:** I appreciate your response. I also wanted to ask yourself, or I could also ask Steffi from Music Therapy Association of Ontario—maybe I'll share the questions a bit—about the Canadian Music Therapy Fund. Is that something that would be pretty significant, whether it's included in Bill 121 or whether Ontario looks at arts as part of our public health strategy, part of our health care strategy? Would it be beneficial to have an Ontario music therapy fund or some opportunity to support music therapists and the phenomenal work you're doing?

1730

**Ms. Steffi Friyia:** I think they offer a really good funding model for us to follow in terms of how they fund music therapists to go into the communities. I think that is what we want to have access to. Beyond that, it will be depending on how things go, I guess. But that is what I want to highlight: that they are very good at strategically looking at how to get the money to the music therapist, to those that need it.

**MPP Jill Andrew:** And that is the Canadian Music Therapy Fund, right?

**Ms. Steffi Friyia:** Yes.

**MPP Jill Andrew:** Okay. So maybe it's something we need to look at provincially as well too.

In terms of your work with families, can you speak to how long a therapy session might be? Is there a better time of day? Because I'm also thinking, as a caregiver, you kind of have to be there. How do you work around the family needs to support the people that you're serving?

**Ms. Kaitlyn Aquino:** Yes, that entirely depends on the family and who you're working with. You'll find that certain times of day are better for some clients. Maybe in the morning they're more mobile, their voice is better, their speech is better, and then, later into the day, they might find more personal expression. So it's really working with the family collaboratively to see when I can provide care.

As to length of session, that also depends on how much someone can tolerate. Someone may be able to tolerate an hour of music therapy, while another resident or someone in-home, maybe 20 or 30 minutes is all that they're able to handle until we're able to build out more. This really depends on the assessment done by the music therapist.

I want to acknowledge that music therapists do use standardized assessments, interventions. We are making goals and objectives. We are looking at this critically, objectively to make sure that we're making an appropriate plan of care that is going to benefit who we're serving.

**Ms. Steffi Friyia:** I think I'd just add one point, which would be that, coming out of the pandemic, online services, though not as effective as in-person always, do offer a place for accessibility for the families because we can change it around their time, their schedule, as well. So I just want to add that.

**MPP Jill Andrew:** Thank you. I'm always cognizant of the digital divide. I know, just thinking of my mom, who has a flip phone—

**The Chair (Mr. Steve Clark):** There's one minute remaining.

**MPP Jill Andrew:** —online hasn't been as helpful, and I know that's the same for many community members. But I really appreciated learning about music therapy today in this context. It seems outstanding.

My last little bit would be for Kenneth with Eli Lilly. I just want to thank you for your first recommendation that the bill support the creation and permanent funding of an entity like a Cancer Care Ontario. You're talking about sustainability and stability, which are things that we've been consistently hearing aren't always the case in our health care system. Bill 121 is a good start, but can you just say a few words on the need for stable funding?

**Mr. Kenneth Custer:** Sure. I think that one of the reasons we drew the parallel to Cancer Care Ontario is because that's been a successful model where you have a provincially established patient care system that has durability, not just—

**The Chair (Mr. Steve Clark):** I'm so sorry to interrupt you, but we're finished with this round of seven and a half minutes. There will be another one coming up.

We'll move to the independent member. You've got four and a half minutes.

**Ms. Aislinn Clancy:** You can continue, sir. Thank you, Kenneth. Hi. I'll ask you to finish your thought.



**Mr. Kenneth Custer:** Okay. I'll move quickly.

Again, to get something where there's some confidence and durability and stability in the structure, in funding—and this entity, I think we could bring in the right experts and stakeholders within the province to understand what elements. We've heard of some great elements today that need to be included in a coordination of care and a holistic wellness package that patients will certainly benefit from.

At Lilly, we're excited about anti-amyloid therapies for the treatment of Alzheimer's, but we also recognize that's one small piece of a more coordinated care provision for patients.

**Ms. Aislinn Clancy:** Thank you.

I wanted to appreciate the insights, too, of our music therapist. My grandma died of dementia. The last thing we could do—we wanted to spend time with her, but really singing old campfire songs and church songs was kind of all we could do in terms of engagement. It meant a lot to us as family members to have some way to interact with her when she lost a lot of her speech. So I do appreciate the work you do, and I know that it's a big hustle to be your own small business. That comes with a lot of stress and administrative burden, and so I appreciate the tenacity of both of you advocating for your profession.

Are you covered under many insurances? Because I know my social work college was good at advocating to have recognition and coverage for insurance. Is that something you're also pursuing? I know it's a step towards OHIP coverage, but—

**Ms. Kaitlyn Aquino:** This is a tricky area that music therapy is navigating. So within music therapy, there are different systems. If you think of physiotherapists, there are neurophysiotherapists—different areas of specialty.

Music therapists do not have, obviously, an Ontario college of music therapy. However, many music therapists do decide to pursue additional education in psychotherapy and join the college of psychotherapy.

However, music therapy does go beyond psychotherapy in terms of rehabilitating gait, speech—there's so much more to it than that. For example, I and also Steffi are trained in neurologic music therapy. We work a lot—rehabilitation, stroke, Parkinson's, brain injury. So that's something as a profession that we are trying to figure out and navigate because music therapy does need to be recognized as its own entity.

**Ms. Aislinn Clancy:** No, I appreciate that. I know it's a hustle to be your own boss, and I appreciate that it could be easier if we had more coverage and more opportunities to have you be paid for your expertise.

I'll bounce it back to Kenneth. We just heard from a couple of geriatric specialists saying that they get paid a fraction of what other specialists cost. They get into it because they love it, but they're finding that that's a challenge for having more docs get into those types of care. I don't know if that's something you feel comfortable responding to, just in terms of creating the infrastructure.

**The Chair (Mr. Steve Clark):** There's about a minute remaining.

**Mr. Kenneth Custer:** Absolutely. I mentioned earlier in my opening statement that we've been going out into the community, meeting with leading centres and the patient community to really get their feedback and help us understand what deficiencies there are in the current care pathway that could be filled in through coordinated efforts like the one we're proposing. Certainly, there's a clear shortfall in the number of gerontologists that are out there, and they'll be critical, both to provide better care the way we're discussing today, but, certainly, as we bring in new therapeutics, we think that's at least a new tool for them to begin to leverage in concert with other specialists to provide some meaningful slowing of disease progression.

**Ms. Aislinn Clancy:** Thank you. I also have to go.

I do want to thank MPP Smith and MPP Kusendova-Bashta. I'm really optimistic about how this will unfold. It was great to see so many folks with expertise sharing their knowledge today. I really appreciated those insights. Thanks to both of you, I'm very supportive of the bill. Hopefully we can make sure it's well funded and that, when the reports come out, we can follow those recommendations so that we can realize these ideals that we want.

**The Chair (Mr. Steve Clark):** We'll now move to the government's round of seven and a half minutes. MPP Smith.

**Ms. Laura Smith:** Through you, Chair, I want to sincerely thank you for spending the time with us today and providing insight into the programs that you're involved in.

I'm going to tell a little sweet story because it's the end of the day and I'm getting a little tired. But one of the things that I remember and I recall quite vividly with my own mother was that music was the ultimate therapy when she was agitated and she was in distress. Quite often, I would find myself turning on the Turner network just so I could get out the door because it would provide that familiarity—because, as we all know, that familiarity of 30 years ago, 40 years ago, was far closer than reality.

In my previous life, I was the parliamentary assistant for tourism, culture and sport, and I had a partnership with the national ballet. They had a screening called *Dancer Not Dementia*, where prima ballerinas who were struck with dementia would, once hearing music, stand up and start dancing, because the left brain and the right brain are such different dynamics, and the muscle memory never lost that ability.

But anyway, just circling back to some of the insight—and I'm going to get back to you, Kenneth. I appreciate what you're providing as well. Can you talk about de-escalation techniques very specific to person-centred dementia and how that integration in the PSW training could possibly help the province, dementia patients, dementia families and dementia care providers?

Actually, it can go to either Kaitlyn or Ms. Friyia, or both.

1740

**Ms. Steffi Friyia:** I think giving the PSWs the insights to what music therapy is all about and then having them

learn what the familiar music is of those who are in need of the de-escalation can provide the PSWs with songs to sing in those moments of tension just to bring them back into reality. Breathing with them and then just—even as simple as just humming *You Are My Sunshine* and just being in front of them and just being a presence sometimes will get them to breathe a little bit and start to come back to the reality and start to sing with you. That’s what I’ve seen.

**Ms. Kaitlyn Aquino:** I agree with those for de-escalation techniques. I think when it comes to PSW training, one of the main things I’ve found when I go into homes is I’m walking around with the guitar, I’m walking around with an instrument cart, and I’m seen as the entertainment; I’m coming to play for residents. When it comes to training, urging that I am here to address specific goals, specific needs, and not so much just to provide entertainment. When it comes to training, if PSWs have the knowledge of what I’m here to do, then they can recognize, “Hey, this is a person who does struggle with agitation, who does struggle with anxiety; when you’re here, can you prioritize this? Can you go see them and see if this would be an appropriate referral to music therapy?”

**Ms. Laura Smith:** Thank you.

Now I’m going to switch gears for Kenneth. We talked about the possible impacts of therapies specific to dementia and Alzheimer’s. My uncle was on an inhibitor, and we knew that, if he stayed on his memory pill, he was less likely to, let’s say, get into trouble. Can you talk a bit about some of the therapies right now that our province or our country is facing and what the impact would be in delaying the processes through these initiatives?

**Mr. Kenneth Custer:** I think I mentioned in my opening statement that Lilly has been working for 35 years to uncover new therapeutics in the area of Alzheimer’s, particularly with an emphasis on uncovering disease-modifying therapeutics. So, while there are inhibitors today, like the ones you mentioned, that are an important component of dementia care in Canada, and they do provide improvements in cognition and activities of daily living, unfortunately, they don’t slow the progression of the disease.

**Ms. Laura Smith:** They stay at one level, and if they stop, then—

**Mr. Kenneth Custer:** Correct. They immediately revert to where they would be without them.

**Ms. Laura Smith:** Yes. Correct.

**Mr. Kenneth Custer:** We are optimistic about this new era of treatment that we see coming. We currently have a medicine called donanemab under consideration at Health Canada right now, and it has shown in two adequate and well-controlled trials to reduce both the rate of cognitive decline as well as decline in activities of daily living by about 35% and 40%, respectively. We think this is very meaningful.

As was mentioned earlier, the one caveat is that you need to—they seem to work better the earlier you intervene. When I mentioned earlier, “Time is brain,” I sort of meant that. It’s a sad thing to say, but you’re going to get

a better outcome, I believe, if you intervene at, say, the stage of mild cognitive impairment as opposed to mild or moderate Alzheimer’s. When we delay the regulatory approval or the access to these medicines, we’re probably taking a cohort of individual people who would have benefited from these medicines and, plausibly, pushing them outside the window of opportunity to benefit from them. So for an individual person, I think it means a lot.

**Ms. Laura Smith:** When we talk about this window of opportunity, could you speak to the specific elements of this bill that you believe would have the most significant impact, particularly in terms of enhancing the quality of care of these patients, whether it’s in long-term care or community services or living at home?

**The Chair (Mr. Steve Clark):** There’s one minute remaining.

**Mr. Kenneth Custer:** I think from my perspective, timely access to a diagnosis is going to be critical. Already, I think we have challenges securing a diagnosis, and there are probably system changes and staffing changes that could improve that. But there’s another element with these emerging therapeutics, which is that you need a confirmation of amyloid pathology. Right now, that can be accomplished with PET imaging, which is complex. It can be accomplished with lumbar punctures, looking at cerebral spinal fluid levels of A-beta. We hope that in the future it will be addressable with plasma biomarkers that are much easier to implement at scale.

So, making the investments in the infrastructure to speed these molecular diagnostics alongside the caregiver and staffing changes that we need in order to really address patients quickly is going to be critical.

**Ms. Laura Smith:** Plasma markers seem to be kind of the catchphrase because before we were talking about very invasive things that, just for the purposes of this room, would be very disturbing for not only the patient, but the families as well.

**The Chair (Mr. Steve Clark):** Thanks, MPP Smith. That ends your first round.

We’ll now move to the official opposition. MPP Vaugeois.

**MPP Lise Vaugeois:** Thank you so much for being here.

Music: mind, body, spirit. We know that music is so powerful. For example, in the residential schools, Indigenous music was forbidden because it’s powerful. We know that music is used in torture because it’s powerful and it affects people on such a deep level. So I really respect the work that you do to really understand and work with people’s needs.

I know my partner’s mother had Alzheimer’s. She listened to opera—loved opera her whole life, but when she was sick, actually, she couldn’t stand it anymore. She needed something different. I wouldn’t know, but you would, so I think it’s very important, and I hope to see support for the work that you’re doing. What I know for myself is that it changes everything. It changes your physiology. It changes your mood, your mindset—if you know what you’re doing. So I appreciate that very much.

And also the distinction between music, wellness and music therapy: I’ve probably been involved a lot in music

wellness—we're at the end of the day, so I'm relaxing a little bit too. As a member of the National Youth Orchestra, I was part of a group that was sent out to hospitals, nursing homes and prisons to perform. Probably the most impactful—well, it was all impactful, but in what we called nursing homes in those days, you couldn't always see the response from people, but then, if you went and spoke with people afterwards, it was very clear that something had happened and had been enriching. Again, you take that much further, and I appreciate that.

Now, Kenneth, I was also looking at your recommendations, and I see also that in the Alzheimer Society's pre-budget recommendation, they talk about appointing Ontario's first-ever dementia secretariat. That to me sounds a lot like the creation and permanent funding of an entity like Cancer Care Ontario—so in other words, an organizing body that then has an overview and is able to guide the coordination and make sure that all the pieces fit together. I think that's a good recommendation that's echoed elsewhere.

Obviously, the diagnostics infrastructure—and I think that we heard this from people here earlier today, about how important it is to get a diagnosis early, and that, at this point in time, the pieces aren't necessarily in place to facilitate that for enough people. But that is a goal, I think, of this bill to, again, pull those pieces together one way or another to facilitate that easier access. As you know, I do support the bill and expect it to go through.

Then, the third recommendation—I think you're referring to sometimes that the medicines can't get approval quickly enough. We've heard that from cancer patients as well, that sometimes there are innovative treatments available that are approved at one level, but somehow it gets blocked before it gets to another level. So I think that's another very good piece of advice, just to, again, give us all a heads up. Sometimes we in government don't necessarily know exactly where those blocks are—they might be at the administrative level somewhere—but we are in a position to figure them out and facilitate that movement, particularly when it's drawn to our attention that there are blockages keeping people from accessing everything that they need.

1750

I think that's probably a good place for me to stop.

**The Chair (Mr. Steve Clark):** I can move to the government's final round of questioning?

**MPP Lise Vaugeois:** Yes.

**The Chair (Mr. Steve Clark):** MPP Pierre.

**Ms. Natalie Pierre:** Thank you to all of this afternoon's presenters. We know everyone's really busy and just appreciate the effort that you've taken out of your busy day and your lives to come here and share your thoughts with us.

The first question I have is for Steffi. I'm wondering if you can just share with us your thoughts around person-centred care and the impact that that has on the quality of life, not only for the patient but also for their family. You talked a little bit in your remarks about evidence-based therapy, so I'm wondering if you can just expand on that a

little bit and tell us more about the effectiveness of music therapy in reducing behavioural symptoms or improving cognitive function.

**Ms. Steffi Friyia:** I apologize, can you repeat that last part?

**Ms. Natalie Pierre:** Sure. It was a couple of questions there. The first one is just around person-centred care and the impact that that has on the quality of life for both residents or patients and their families.

**Ms. Steffi Friyia:** Definitely, I think we've had remarks on the importance of music and sharing that with both persons with dementia and those who are caregivers. One thing—and I think I have it in the written statement—is that caregivers have reported that there is a decreased level in burnout when they can have moments where they can share those music moments and they can feel connected, or reconnected, with their loved ones again and feel less of just seeing the symptoms and more seeing who they were and who they are be presented.

In terms of the person-centred care, knowing what music is enjoyed—for example, knowing that, okay, opera didn't work; what other music could work in that instance—and working with the family and working with the patient to see what would bring out the best for them and what would reduce agitation, that's a lot of work. It takes time, it takes getting to know each individual client, but it's well worth it.

**Ms. Natalie Pierre:** The second part of the question was, what kind of evidence? You mentioned that briefly in your remarks, about evidence-based therapies. If you could just comment on how music therapy helps to reduce those behavioural-type symptoms or even improve cognitive function.

**Ms. Steffi Friyia:** In neurologic music therapy, we do a lot of working with the brain and going through rhythmic entrainment, the way the neural networks work. That is one part where the brain continues to function, and they can hear beats and they can learn to walk with that. So, learning to walk to those beats or, when it comes to singing and using vocal intonation therapy, learning to maybe sing together and then focusing on the goals of the patients and whatever their needs are.

Music—not only familiar music but just music in general, just having a guitar and playing those chords and giving them instruments to play—can help with functionality in terms of continuing to keep the beats and things like that.

**Ms. Natalie Pierre:** Thank you.

The next couple of questions I have will be for Kaitlyn. I'm wondering if you could speak to specific elements of the bill that you think would have the most significant impact, particularly in terms of enhancing the quality of care that's available to patients and reducing strain per-haps on community services and long-term care.

**Ms. Kaitlyn Aquino:** So at this point, the biggest barrier really is access. I've talked about how music therapy is not necessarily being funded in homes through the Canadian Music Therapy Fund. It is, but today, when I was at work, I was talking to the director of programs and they're telling me, "I'm having to be resourceful. How can I have you

here for more time, for more days?" It's not in the budget and so it can be very difficult even to get in the door and have a conversation that this would be beneficial. Or I'll speak to someone at a hospital program, and they'll say, "We would love to have this service. We see the evidence. We see the research. We've seen the videos. We understand why it works, but we don't have the money to fund this," and that's kind of where the conversation ends.

So in order for Ontarians to have access to this care, definitely funding initiatives and support that way is top priority so that you can even access the service in the first place.

**Ms. Natalie Pierre:** Thank you.

And then I guess my next question will be for you, Kenneth. You talked a lot about diagnosis and early diagnosis, earlier treatment, better quality of life for patients or residents and better health outcomes for them—and better quality of life, I guess, by extension for their families and for their caregivers as well. So I'm wondering if you can talk a little bit about stigma. It's something that we heard a little bit from a number of presenters earlier today and the effect of stigma surrounding these conditions often can prevent early diagnosis and delay that kind of critical care.

**The Chair (Mr. Steve Clark):** There's one minute remaining.

**Ms. Natalie Pierre:** So I'm just wondering if you have any thoughts on that that you'd like to share with us.

**Mr. Kenneth Custer:** Absolutely. It's a major issue. I think there's a lot of underdiagnosis in this disease, and that's underdiagnosis of patients that could benefit from therapy if they were diagnosed in a timely fashion. We've, I think, heard that about 50% of individuals indicate that fear of the diagnosis itself or associated stigma has been a barrier to getting that diagnosis. So I think the more we can do through provincial campaigns to raise awareness about Alzheimer's and what you can do about it would be hugely beneficial in eliminating some of that stigma.

**Ms. Natalie Pierre:** Thank you, Chair. I'll leave it there.

**The Chair (Mr. Steve Clark):** I want to thank all of the presenters for your very insightful addresses this afternoon. I want to say to everyone, both the three of you and all the presenters today, and in fact, because we were over-subscribed, to anyone who was unable to present in person: The deadline for written submissions remains 5 p.m. on Thursday, October 10. So if there's anything additional you want to provide, just please do so to the Clerk before that deadline.

There being no further business, this committee is adjourned.

*The committee adjourned at 1758.*







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