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## **Official Report of Debates (Hansard)**

**Wednesday 20 November 2013**

## **Journal des débats (Hansard)**

**Mercredi 20 novembre 2013**

**Select Committee on  
Developmental Services**

Developmental services strategy

**Comité spécial sur les  
services aux personnes ayant  
une déficience intellectuelle**

Stratégie de services  
aux personnes ayant  
une déficience intellectuelle

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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

**SELECT COMMITTEE ON  
DEVELOPMENTAL SERVICES**

**COMITÉ SPÉCIAL SUR LES  
SERVICES AUX PERSONNES AYANT  
UNE DÉFICIENCE INTELLECTUELLE**

Wednesday 20 November 2013

Mercredi 20 novembre 2013

*The committee met at 1603 in committee room 1.*

**DEVELOPMENTAL SERVICES STRATEGY**

**The Chair (Mrs. Laura Albanese):** Good afternoon. We call this committee to order.

**MINISTRY OF HEALTH  
AND LONG-TERM CARE**

**The Chair (Mrs. Laura Albanese):** We have the Ministry of Health and Long-Term Care that is here to give us a presentation. Welcome to our committee. I would ask you to start by stating your name and your title before you begin. You have up to—what is it? Do you know how many minutes of presentation we have?

**The Clerk of the Committee (Mr. Trevor Day):** Thirty.

**The Chair (Mrs. Laura Albanese):** Up to 30 minutes of presentation, followed by a round of questioning by each party. You may begin.

**Ms. Catherine Brown:** Terrific. Thank you. My name is Catherine Brown. I'm the assistant deputy minister of the health system accountability and performance division at the Ministry of Health and Long-Term Care.

**Ms. Tamara Gilbert:** My name is Tamara Gilbert. I'm the director of the implementation branch at the Ministry of Health and Long-Term Care.

**Ms. Catherine Brown:** Thank you for having us here today. I wanted to take you through a presentation on some of the linkages between the developmental services sector and the Ministry of Health and Long-Term Care.

Just a little bit of context. As you all are well aware, the Ministry of Health's mandate is to establish strategic direction and provincial priorities for the health system—  
*Interruption.*

**Ms. Catherine Brown:** Is that me? Is that okay? Can you still hear me? Okay.

We establish services and set policies for how services are provided for all people who live in Ontario, including every specific population, including those persons with developmental disabilities.

There are several programs and initiatives that serve persons with developmental disabilities, including primary care, mental health and addiction services, home and community services, and long-term care. I should say

that all health services are equally available to anyone in Ontario as they would be to someone with a developmental disability, but there are some additional services or linkages that are provided for people with developmental disabilities.

The ministry released an action plan for health care in 2012 that provides a commitment to ensure Ontarians get the best health care where and when they need it—right place, right time—and ensuring that, where possible, services are available to people in the communities where they reside. To that, that same principle applies as we provide services to people with developmental disabilities, whether in their home, in a residential setting or other setting, or whether they come into the health care system, into the hospital sector or into the long-term care sector.

The ministry is committed to care in the community, as you know, so that there are more options available to people to stay home longer and to ensure that we provide supports where people live. This year, the ministry invested an additional \$260 million in the home care sector, and that was to increase home and community services to all clients and provide faster access to services from PSWs for complex patients at home and also for nursing services people at home to try and ensure that people have services within five days of being assessed for discharge.

On page 4, I just want to talk about, as I mentioned earlier, some of the areas where we provide programs and initiatives that serve persons with developmental disabilities.

So to page 5: Primary care in Ontario and in Canada has evolved, as you know, from a predominantly fee-for-service system where doctors billed the system in a service-based system. Those mechanisms still exist in many ways, but we have also evolved to providing services in group settings and family health teams, community health centres and also looking at other disciplines and how they might provide health care services. The focus of primary care is illness prevention and health promotion, and also dealing with people who have illnesses and ensuring that they are referred to specialties as need be.

Services are available to all insured Ontarians, as you know, and there are incentives incorporated into some physician payment models to encourage the rostering of

patients; that means taking patients into their care. We provide incentives to certain physicians in certain settings to take on more complex patients. For example, in a family health team we have a service that is called Health Care Connect that tries to find primary care physicians for people who do not have a primary care physician. As you might imagine, we can't make physicians take patients. We encourage them and ask them to put their names forward, that they're still accepting patients. Sometimes complex patients are not the top of the list for physicians who have a full workload. So we offer incentives to physicians to take complex patients into their roster and provide care to them. That is to ensure that some of the harder-to-serve patients continue to find access to physicians, just like those who are easier to serve.

Health Care Connect was launched in 2009, and since its inception—that is the service that connects patients with a primary care provider—approximately 240,000 patients have been referred to a primary care provider, and of that group, more than 23,000 of those are identified as complex patients, so a good number of those. That doesn't mean that only 10% were complex, but we believe a good number of the complex people have been matched up with physicians.

We also have a program of house calls. House call services were enhanced in 2012 for patients with complex needs who are unable to travel to a primary care provider or where access is easier and better managed at home. Those house call programs provide services from a range of health providers, such as a doctor or a nurse or an occupational therapist. It also offers phone and online consultations. So it is a service that takes the care to where the patient lives, at home, in addition to services that are provided through other home care avenues, like through a CCAC and the regular home care that the health care system provides.

#### 1610

We also have a developmental disability primary care initiative which promotes and enhances the primary care of adults with developmental disabilities by providing primary care providers with training and tools and guidelines, as well as the research and evidence-based evaluation that helps to inform those tools on the special needs and challenges of the persons with developmental disabilities, to both help physicians, first and foremost, provide better care to people with developmental disabilities but also to ease the burden of a physician who is perhaps reluctant to take more complex clients because they don't know how to manage them. This helps to provide them with the tools and the guidelines that might encourage them and ease their ability to be able to care for those more complex patients.

To date, that program has published the Canadian Consensus Guidelines for Primary Health Care of Adults with Developmental Disabilities, produced clinical tools to help implement the guidelines, and delivered training to 179 primary care providers—physicians and nurses as well as nurse practitioners. To further enhance access to

and quality of care for adults with developmental disabilities, the clinical support network developed through this initiative also reaches out to physicians who are providing care—and nurses and nurse practitioners—to help provide peer guidance and mentorship and foster discussion amongst those providers to enhance the care that is provided to people with developmental disabilities.

The next area I wanted to touch on, in slide 6, is programs for people with mental health and addictions who also have a developmental disability. The language that is used to describe that population is of a population with a dual diagnosis: They have a mental health disability as well as a developmental disability. From our estimates, there are approximately 23,000 adult Ontarians with a developmental disability as well as a mental health problem.

The ministry funds over 300 community-based mental health agencies to provide a range of services. Those are mental health agencies available to anyone with a mental health issue. In addition, they're also delivered, as you know, in some acute and tertiary care facilities. We have specialty psychiatric hospitals, and we also have mental health beds in many of our acute care hospitals through the province.

Dual-diagnosis-specific services and programs are available to the population I described who have both a mental health diagnosis as well as a developmental disability. Those agencies provide services to that population and also ensure that they are linked to community supports and providers who can better manage their needs as they need them managed.

In 2011, the Ministry of Health, together with the Ministry of Children and Youth Services and the Ministry of Education, announced a Comprehensive Mental Health and Addictions Strategy, as you may know: Open Minds, Healthy Minds. That strategy looks to create a more coordinated, responsive, client-centred mental health and addictions system throughout the province. The first three years of the strategy were led by MCYS, as the focus was on children and youth with mental health issues. In 2014, the strategy will be expanded to include addictions and adult mental health, and will be led by the Ministry of Health and Long-Term Care.

We're currently developing that four- to 10-year action plan that's picking up on the one- to three-year plan that was focused on children and youth. We are currently working the Ministry of Community and Social Services and other stakeholders to look at creating a dual diagnosis framework that would set out expectations for the services provided to persons with developmental disabilities who also have a mental health diagnosis and to improve delivery of services and programs to that population to make sure that it is more understood and more available to people with developmental disabilities throughout the province.

I should also note that, in 2012-13, the province allocated \$960 million for community mental health and addictions, \$778 million for community mental health

care in Ontario and approximately \$182 million for addiction programs for over 160 substance abuse and problem gambling treatment programs and provincial initiatives. Those programs are all equally available to people with developmental disabilities, but also some of those have a population of providers who have a particular expertise and have been trained. We're looking to build on that in our year four-to-10, because it wasn't a concerted effort; it has just evolved that way. So we're hoping to strengthen that in our next round of work.

I will speak to the last point on page 6. In 2008, the Ministries of Health and Community and Social Services updated a joint policy guideline for the provision of community mental health and developmental services for adults with a dual diagnosis—that population I just discussed—and we continue to work to support the implementation of that guideline, and that guideline works to reinforce the mental health and addictions strategy. If it would be helpful, I can make copies of that guideline available to the committee, if you would like.

Turning to page 7 to speak a little bit about home and community care: As you know, there are 14 community care access centres in the province, and they serve to provide community services and home care services, to both coordinate and deliver services, and to manage long-term-care home wait-lists and admissions, as well as placement for adult day programs. They look to help with supportive housing and to manage chronic care and rehab programs through the hospitals.

Home care services: The eligibility requirements for CCACs are established in regulation under the Home Care and Community Services Act and do not distinguish disease or ability level to ensure that services are equally available to everyone in the province. Services include nursing, personal support and homemaking, occupational therapy, physiotherapy, speech-language pathology, nutrition and social work. Services are delivered in a variety of settings and are provided, as well, to eligible children and youth in public and private schools and to those who are being home-schooled.

Currently, over 637,000 clients receive CCAC services in the province, including home care, long-term-care placement, as I mentioned, school, health and professional services. In 2013-14, this year, the ministry will provide local health integration networks. I'm sure you're all familiar that local health integration networks are the body that plans and funds health care services at the local level, and those are agencies of the crown. The local health integration networks were provided with approximately \$2.3 billion in funding for CCACs, and that funding has grown exponentially over the last 10 years, about 92% since 2003 and 2004. The bulk of that growth is twofold: It's representative of population growth, but it's also representative of a dedicated effort to enhance and expand access to services at home and to help people to receive services where they live rather than in more expensive settings like a hospital.

In 2013, the budget committed to an additional investment in the home and community sector; as I mentioned

earlier, \$260 million. As I noted, part of that investment was to help reduce wait times for patients who require nursing services or those with complex needs. That population with complex needs may often represent some of the population who have developmental disabilities. Often with a developmental disability come complex health needs, and so that population are often harder to serve at home. We've made a concerted effort with the investment to try to bring down those wait times and make services more accessible.

I think that's that for that page. Turning to page 8, the focus on community services and services at home is to continue to promote independence and to keep people in their communities, where they're best supported by family, friends and their neighbours and loved ones. That is also to keep them closer to the people who know their health status—family physicians, primary care physicians—and making sure that they are looked after where they live.

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Community support services are also available at the local level—things like Meals on Wheels and adult day programs. Those services are often targeted towards a population. Sometimes it's the elderly or seniors; sometimes it is a population like people with a developmental disability. One of the complexities of people with developmental disabilities is that they also age at a more rapid rate and see health problems emerging sooner than those without a developmental disability. That presents a growing and complex need for how we support that population as they are aging.

The goal of promoting independence is one that is shared with the developmental services sector, continuing to promote independence for individuals with developmental disabilities, but also continuing to promote independence for people as they age, ensuring that they are able to stay where they live and where they can be best supported. Although these services may not always be targeted to people with developmental disabilities, they are certainly available to that population, with the shared goal, as I noted, of promoting independence and keeping people closer to home. As I noted at the beginning of this section, CCACs are that one link to all of those services locally. CCACs provide a great deal of support to those families and people with developmental disabilities locally, to help them find the services they need and ensure they get the services that they need.

I'd like to speak a little bit now to long-term-care homes. There are currently 633 long-term-care homes in the province, which provide care to 77,000 residents. The long-term-care home utilization, as you all well know, is 99%, and the applicants are prioritized primarily based on need and, as you know, based on choice. Approximately 4,500 residents with developmental disabilities currently live in long-term care. So about 6% of residents have developmental disabilities. Long-term care—these two facts are unrelated. Sorry. The overall envelope for long-term care is about \$3.8 billion. That's the full envelope. That's not for that 6%.

Long-term-care homes are places for people who need assistance with activities of daily living and access to 24-hour nursing care or supervision in a secure setting. Generally, the eligibility criteria for long-term-care homes are the same for all applicants, with no specific criteria for persons with a developmental disability, so it's age-related and capacity-related. It is that need for the additional care. There are some notional age guidelines, but, as I noted earlier, for those people who age more quickly or are in need of services sooner, age is not a barrier to access.

Long-term-care homes may be the most suitable setting to meet the health care needs of some people with developmental disabilities; most likely, those would be older adults. We have some examples in the province where, as the developmental services institutional sector was wound down, we have some pockets of places where individuals who were in institutional settings were moved into long-term-care settings, as it was deemed to be the most appropriate place for them. They were aging and needed the supports, and we work in those locations to have the Ministry of Community and Social Services bring their services into the long-term-care home to support those individuals. An example of that is in Ottawa. They're not in large number. Long-term-care homes have the ability to establish specialized units, and there are about seven of those currently in the province. Typically, six of the seven are behavioural units.

As you may know, the complexity of the health needs of individuals going into long-term-care homes is growing. People are more acute when they get there. People don't move to that level of care when they are still healthy and able to look after themselves, as they may have done 15 years ago, but now move into that level of care when they are no longer able to look after themselves. Often, families and individuals choose to go there as their last place and choose to remain home as long as they possibly can. So we see the level of acuity increasing as people move into long-term care, and with that often comes dementia and behavioural issues. Sometimes, long-term-care homes will identify a behavioural unit to support people who have additional behavioural needs to the rest of the population of the long-term-care home.

To date, there are no designated units for people with developmental disabilities. In preparation for the discussions today, as we talked about this over the last couple of weeks, we talked to the folks on the long-term-care side and to the associations about their views on that. There didn't appear to be a sense that the needs of people with developmental disabilities were sufficiently different, and what we heard back was that the notion of segregating people with developmental disabilities within a long-term-care home was not ideal, but rather to ensure that they had appropriate additional services.

If I can use a different example, if you're someone in a long-term-care home who needs dialysis, there's no reason that you need to be separated. You could be, but there's no reason that you need to be. We can bring those

services to you where you are amidst the rest of the population in the long-term-care home. So the services continue to be provided across long-term-care homes to people with developmental disabilities. Not every long-term-care home has a population with people with developmental disabilities, but as the population ages, and for those homes that are larger, that is certainly a population that they see growing.

Last, but not least, I'll talk a little bit about some of our initiatives. To the point I just made—I'm now on slide 11—care in long-term-care homes and integrated planning for people with complex needs: We have a steering committee currently in place that is comprised of people from the Ministries of Children and Youth, Community and Social Services, Education, Health, and Training, Colleges and Universities that provides recommendations to promote an integrated lifespan approach for serving people with complex needs. Again, this population would be a population that would be included in that. We all have a shared interest in targeting effective and efficient care and look to make that work. We certainly work collaboratively to identify populations that are challenging for our service providers across the spectrum to ensure that we're not separating out or siloing services in a way that makes them more complicated for people to access, but rather looking at how we are going to manage the needs of a diverse population as they age.

The steering committee is currently finalizing their definition of "needs" and scoping the final deliverables. So we're in the early stages of that work, but certainly looking at this population as part of that. I would say that this is a timely opportunity to get your feedback on how we might better incorporate some of your thinking into our thinking as we're doing that work.

The next initiative on that page is community health links. Hopefully, many of you will have heard of community health links. Community health links are focused on improving patient care and outcomes for people with complex conditions. The focus of this is to provide an integrated approach to service at the local level. Community health links were first announced about a year ago, in December 2012. We started with 19 and have evolved—I think we're—

**Ms. Tamara Gilbert:** Thirty-seven.

**Ms. Catherine Brown:** I was going to say, I think we're at about 37 now, but I couldn't find it—there it is. This is a group of providers locally. As a health link comes forward to say that they'd like to be part of this, we ask that they have 65% of their primary care physicians involved and that they are focusing, but not exclusively, on the complex population: 5% of the population is complex and uses up two thirds of the health care dollar. Being able to provide a more coordinated approach to that population helps to make services and funding more available to provide services more broadly.

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What we see locally with community health links is everyone being involved, from primary care to the hospital to the CCAC, but also local and community service organizations, from food banks to housing to long-term care, to look at how they can provide a better continuum of care for a patient, a single care plan, and make it easier for the patient to move through the system and not fall through the cracks.

When we talk to people about their population locally, even in downtown Toronto emergency room physicians and nurses can tell you who their top 100 users are, and certainly in smaller communities where people don't jump from hospital to hospital it's even easier to identify that high-needs population that resurfaces on a regular basis. So the challenge is how we provide care to that population to prevent them from returning to the ER, but rather to provide them with the care where they need it so that their place to go to get care is not the emergency room because they're getting care from the community in which they live and are supported by their primary care provider, as well as other specialties and social services that they need to be healthy where they live.

**The Chair (Mrs. Laura Albanese):** You have about two minutes left.

**Ms. Catherine Brown:** I can talk a little more about research programs and other initiatives, but I think that the slides speak for themselves. I will say that there are a number of initiatives going on locally, where health and social service providers are working to come up with innovative ways to serve this population. But what we have found is that we are best able to do that when we put our minds together, like with health links, to not look at not just one particular population and hive them off from other populations but to see how best to serve the complex needs of a population of people as they age or where they live. That shouldn't necessarily take a devotion to a particular population, but certainly an understanding of what the population may need and how those services may differ.

As I spoke about earlier, there is lots of work under way to continue to provide that guidance to primary care physicians and to other providers in the health care sector to help them better serve this population, whether in their community, in a long-term-care home or in a hospital.

So I will stop there.

**The Chair (Mrs. Laura Albanese):** Thank you very much for the presentation. Ms. Elliott?

**Mrs. Christine Elliott:** Thank you very much, Ms. Brown, for coming this afternoon and for your presentation. I do have a few questions. I'll just start by going through your slide deck, if I could. On page 5, you talk about primary care services, and I see some of the research that's being done. I just read your last slide about the concerns you have about people with developmental disabilities being able to access primary care. You talk about incentives and the fact that you're trying to persuade physicians to take on these complex patients. Is there any plan for any—I wouldn't say financial incen-

tives, but even taking a look at the payment schedule to see if there is some room to manoeuvre there, because it often takes much longer to take a history, for example, with someone who has a developmental disability. We talked about that a little bit in the mental health and addictions subcommittee as well. Is that something that you're taking a look at? Are there any other financial or other incentives to incent physicians to take on these complex patients?

**Ms. Catherine Brown:** I don't know the answer to that, but I will certainly take that back and either find out if we are or provide that information to both my deputy and my colleague who looks at the OMA negotiations and the funding for physicians. I think that's a valid consideration and we can certainly take it back. There may be work already under way to your point. If it's been previously recommended on mental health and addictions, it's possible that we're already looking at that on the developmental services side. I'm not aware of that, but I will look into it.

**Mrs. Christine Elliott:** All right. If you could provide us with any information that might be relevant to the work we're doing, I'd appreciate it.

**Ms. Catherine Brown:** Certainly. Yes, I will.

**Mrs. Christine Elliott:** Thank you. You also talk about house calls being enhanced in 2012 for patients with complex needs, and I was wondering if you keep statistics of the needs that you're serving with these house calls, specifically to see how many people with developmental disabilities would be served through the house calls program.

**Ms. Catherine Brown:** I will take that one back as well. I don't know. My guess would be no, because we would look at what service was provided, as opposed to—we would know age; we would be able to break it down that way, but I'm not sure that we would have data on people with developmental disabilities. But I will look at that and let you know if we can break it out that way at all—

**Mrs. Christine Elliott:** Thank you.

**Ms. Catherine Brown:** —or if it ever has been.

**Mrs. Christine Elliott:** On page 11, you speak about the ministry's initiatives in the steering committee amongst the various ministries. I noticed that you're currently finalizing the definition of "complex needs." That being the case, I'm assuming it's going to take some time for the committee to do its work, if you're still working on the definition of what complex needs are. Can you give us some idea of what the time frames are for this committee to do its work?

**Ms. Catherine Brown:** The committee is—I appreciate that the definitional piece has taken some time, and it is because we all have very different complex populations under our purview, so it's ensuring that we're comprehensive in that, and that it speaks to the needs of all of the ministries and their respective populations.

That being said, once we have the definitional work done, our hope is to begin providing advice within six months, and to continue to do so over time, rather than to

finalize a report, let's say, by the end of a year, but rather to start formulating advice as quickly as within the next six months.

**Mrs. Christine Elliott:** Thank you. And with respect to community health links, you've indicated there that it could include a focus on those with developmental disabilities. My understanding of health links is really that it was to deal with people who have complex physical needs, multiple complex needs. I'm wondering if people with developmental disabilities and their needs are really going to be a focus of health links.

**Ms. Catherine Brown:** If I said that there would be a focus, I didn't say that properly. Health links are focused on a complex population, not exclusively. So they're focused on a geography, to begin with, as you know, and within that there would be several primary care physicians, up to—our goal is 65% within that geography, 65% of the patients. That means that many of the patients will be complex, but many will not. The focus for health links is to ensure that that complex group has a care plan, has a primary care provider, that everybody understands what their needs are and how to best serve them in that way.

I think what I was trying to say was that it would necessarily mean that people with developmental disabilities would be in that population because they would have complex needs. There's nothing additional that's being done, or differently that's being done, to say within that how we would better serve people with a developmental disability, but rather to say how to reach out to the most complex patients within our population. That, to me, would include people with a developmental disability who have those additional complex health needs.

**Mrs. Christine Elliott:** Thank you. I believe my colleague has some additional questions.

**Ms. Sylvia Jones:** Thank you. I am most interested in page 9, where you make reference to the long-term-care facilities. So from your slides, you talk about 4,500 residents with a developmental disability currently living in long-term-care homes. That concerns me. Can you tell me the average age?

**Ms. Catherine Brown:** No, I can't. But I can see if we can find that out.

**Ms. Sylvia Jones:** Yes, if you could provide that to the committee, because anecdotally I have examples in my own community where people who in no way would be considered appropriate in a long-term-care facility are being housed there, and they're certainly not getting any outside day programs assistance appropriate for their level of where they're at.

**Ms. Catherine Brown:** People with developmental disabilities?

**Ms. Sylvia Jones:** Yes.

**Ms. Catherine Brown:** Okay.

**Ms. Sylvia Jones:** Yes. So a family goes in crisis, and there are no services available, no group home options. So they get housed in, plunked in, a long-term-care facility. There are no outside integration activities that go with that. It's literally, "We need a bed. We're in crisis,

so there we go." That's why I'm most interested in, if you could share with the committee, the average age of those 4,500.

There was a recent report that came out; it's a joint study by CAMH. It talks about how adults with developmental disabilities are not getting proper primary care. Has the ministry studied that report? Are they looking at how to solve that problem?

**1640**

**Ms. Catherine Brown:** I'm going to ask Tamara to comment on that. We are looking at the report. My understanding is that the piece that they've released is their preliminary findings.

**Ms. Sylvia Jones:** Correct.

**Ms. Catherine Brown:** We're looking forward to the more detailed piece so we can look at how we can respond to that and build on that. But I'll ask Tamara if she wants to—

**Ms. Sylvia Jones:** So was this news to you?

**Ms. Tamara Gilbert:** No, it's not. I would just build on what Catherine said to say that we are aware that the executive summary of the report has come out. The final report is due in December sometime, and I think we're keenly interested in seeing that final report and understand, as you do, that it does have its focus on the DS population and access to primary care.

**Ms. Sylvia Jones:** So you'll wait until December?

**Ms. Catherine Brown:** We're looking now at what we can do to better serve complex populations. Your comment—was it a surprise to us? I don't think it was a surprise to us particularly, but it is important for us; the work that ICES is doing and will be submitting in December will help us to understand hopefully a little bit more about what's behind it. I think the comments that were made by Ms. Elliott about the time it takes to take a record to understand what's going on with a patient who has a developmental disability are things that we may not typically take into consideration. We're very much looking forward to seeing what the ICES provides for us to better inform how we might look at things like billings and other ways to better augment services. The other piece that we struggle with is the ability to refer complex patients to a primary care physician. Part of that is the incentive, but sometimes the incentive doesn't do the trick. So what are the ways to help to ensure that people get the care they need when they're complex?

**The Chair (Mrs. Laura Albanese):** Forty-five seconds.

**Ms. Sylvia Jones:** Back to the 4,500 residents: Can you provide to the committee how that number has changed—three years ago, five years ago, 10 years ago? Where is that on the continuum? Going up? Going down? I'm going to guess it's going up dramatically, but—

**Ms. Catherine Brown:** I'm going to guess that, too, but I will go back and see what we can pull out of the data.

**Ms. Sylvia Jones:** Thank you.

**The Chair (Mrs. Laura Albanese):** Thank you. We'll move over to the NDP.



**Ms. Cheri DiNovo:** Thank you for the presentation. I'm going to pick up where Ms. Jones left off. In terms of, again, young people with developmental disabilities taking beds in long-term-care homes, where the vast majority of those residents are seniors, I want to know why they're there. What other facilities are open to them? That's a question that you perhaps need to answer. It seems to me and obviously to some of us that that's not the best place for them.

Number two: I don't see anything in your deck about wait-lists. I would like to know about the wait-lists for accessibility services. You talk about the supportive housing wait-list; what does that look like? Home care—what does that wait-list look like? How many are on it? We could go through the list, but I don't see any indication of wait-lists.

Anecdotally, from my experience in my riding, people who have children or family members with developmental disabilities wait a long, long time for services. I'll give you an example of a parents' group; it's called Tragically NOHIP. They came here and did a press conference. Almost all of them, for example, with children who had developmental disabilities and addiction issues/dual diagnoses of various kinds had to send their children out of province to get service, mainly residential. Most had to mortgage their homes to do so. As you can imagine, many sent them to the States.

Again, this seems to me a crisis situation. I don't get the sense from your decks that this is a crisis situation. I'm hearing about the crisis from parents. That's number two.

Finally, we of course all know the situation: Parents have had to drop a child off at a ministry office because they couldn't get assistance, and they were at their wits' end. This all speaks to wait-lists.

The final question, I guess, is this one. We have a wait-list problem, we have a services problem, and we have a problem of residential care; how do we address those problems? What is required to fix the situation we're in? Any thoughts—on the last part, anyway?

**Ms. Catherine Brown:** I'll respond to the easy part first—not easy, but we do have the data on wait-lists. Again, I don't believe that it would be broken out differently for—we can look at age, but I'm not sure that we would have, for example, a wait-list for people for home care with complex needs that would then be subdivided into people who have a developmental disability. But I will look to see if we do. Regardless, we do have the broader wait-list data, and we can certainly provide that to the committee.

To your first question on why are they there, I can't speak to the evolution of how those 4,500 individuals ended up in a long-term-care facility. What we do hear from families is that it may not have been their first place of choice for their family member, but they're certainly glad there was something there.

And to your point, it may not be ideal to have a younger person with a developmental disability in with a group of very aged seniors, but for many family mem-

bers, it's better than; that said, I don't know that I could put to paper how they got there, other than, they have evolved over time. I think the question that was asked about "Can we look at how the numbers have changed?" might speak to that, so we'll do that.

On how we address these, I think that there are many aspects of the work that we do that try and address this. I think certainly the work of this committee and the recommendations that you will provide to us for how we might address it will be very helpful and welcome to us. It is a tough nut to crack; there is no question about it. This system often struggles to serve people with particular types of needs that aren't as readily served as some others. So we look forward to the advice that you give to us to help us to meet that challenge.

**Ms. Cheri DiNovo:** You must have some ideas though, no?

**Ms. Catherine Brown:** I honestly, on this particular population, don't know enough. Some of your questions may help me to understand that better. I don't know enough about the scope of it, and the work that we're doing within the ministries to try and address the population and sort that out will also help me to understand. So at this point, it's premature for me to say.

**Ms. Cheri DiNovo:** My colleague has some questions, but just if I could get the data on the wait-lists, that would be great. Thank you.

**Miss Monique Taylor:** Thank you for your presentation today. I, like others before me, am very concerned about our young people ending up in long-term-care facilities. Although parents may find that it's the best thing at the time, that's because there's nothing else left—it's not the ideal situation—and they would find them better off in communities doing programming that would suit their needs. Are any of those individuals getting programs that do suit their age needs while they're in the long-term-care facilities?

**Ms. Catherine Brown:** Yes. The example I gave earlier—and I can go back and see how many of our long-term-care homes that have a population are providing additional services. The example I gave of a home in Ottawa that has, I believe, between eight to 10 of their population—they have a number of services from the community that come in, and services that they take those residents out to.

**Miss Monique Taylor:** Okay, so there would be an increased cost to those individuals, then, who are associated to that?

**Ms. Catherine Brown:** Services would be provided by the service sector that is funded by the Ministry of Community and Social Services to provide those supports to those individuals—

**Miss Monique Taylor:** At a cost, I'm sure, right? There would have to be a cost associated—

**Ms. Catherine Brown:** Not to the individual; to the system.

**Miss Monique Taylor:** Not to the individual, of course, but to the long-term-care facility. There has to be an increased cost now for that individual to be in that

care facility—more than a senior who wouldn't be receiving those same services. No?

**Ms. Catherine Brown:** No. Services are provided in long-term-care facilities for a cost. The costs are the same for everybody, depending on the type of bed that they are in, and there are cost reductions for populations, depending on their ability to pay. The additional services that would be provided would be provided from the community and social services sector, through funding that is provided to those agencies to provide supports to people with developmental disabilities, whether it was to them in a community setting or in a residential setting, such as the long-term-care home. But neither the home nor the individuals are charged for those services.

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**Miss Monique Taylor:** Okay. I have another question. In a home setting, home care nursing provides a maximum of four visits per day, I'm told. A person who needs catheterization could possibly need five visits per day, but they're maxed out at four. I've been told that people are feeling discriminated against, a very vulnerable sector of people, and I would like to know your thoughts and the reasoning for the ministry capping at four visits per day.

**Ms. Catherine Brown:** The ministry doesn't cap. There are guidelines for what is deemed to be appropriate, just like we provide funding, for example, for a hip replacement and we now have what we call quality-based procedures. So we provide funding for that service. We provide that funding based on an average cost. An average upper limit would be four per day, but there's no hard limit that says you can't have. It would be up to the CCAC to assess the needs of the individual and look at how best to meet the needs of the individual, and what, medically, is necessary and what is necessary to sustain that individual at home.

**The Chair (Mrs. Laura Albanese):** One minute.

**Miss Monique Taylor:** Thank you. That's interesting, because I've been told specifically that people are ending up in long-term-care facilities to get the extra care that they need because they cannot get five visits at home per day, that they're told they're only allowed four, so—

**Ms. Catherine Brown:** I'm happy to provide the information about—

**Miss Monique Taylor:** If you could.

**Ms. Catherine Brown:** —the guidance that's provided to the CCAC on service limits.

**Miss Monique Taylor:** That's great. Thank you. I also would love to know your thoughts and your plans—the ministry's—going forward with the crisis that we're finding in our long-term-care facilities. It's a snowball effect, right? We have young people in long-term-care facilities that were never supposed to be for young people. So what is that we're going to do in the future as this crisis continues to snowball?

**The Chair (Mrs. Laura Albanese):** Miss Taylor, I'm sorry—

**Miss Monique Taylor:** Nope, I'm done. Thank you.

**The Chair (Mrs. Laura Albanese):** —but the time is up, and I have to be mindful of keeping us on time for the vote that is coming later. Ms. Wong?

**Ms. Soo Wong:** Thank you for your presentation. Let me start backwards on your slides. On page 13, you share with us a justice case management program. My question here is: Is this a province-wide program or is this in one geographic area?

**Ms. Tamara Gilbert:** That is a program that is run in the Central LHIN.

**Ms. Soo Wong:** The Central LHIN, okay. My next question here is: With respect to the role of the dual diagnosis case manager, what is their collaboration with other ministries? It's this dual diagnosis case manager that's coordinating services with the client, but what is their relationship with that position and MCYS, the Ministry of Education or other ministries?

**Ms. Tamara Gilbert:** Again, that's a program that's run through the LHIN. I don't have those details at my fingertips, but we can go away and find that out for you.

**Ms. Catherine Brown:** Typically, though, if I can say, on case management functions generally, their primary focus may be within the health sector; for example, leaving aside this initiative, a case manager in a hospital who's transitioning patients from hospital to home, their focus may be on the health needs and the health assessment of that individual, but they do also work across their community to touch in with community and social service providers, food banks, other providers who may need to be engaged in helping to provide those services. First and foremost, their priority would be health care, but they are often involved in drawing those other services.

I go back to the health links—I don't say it as a promotional thing, but it was surprising to many, on looking at the health links, that such an initiative was necessary to ensure that the care that people needed was put around them, rather than them having to go around to the different places saying, "Where do I get food? Where do I get supports for housing? Where do I get home care? Where do I get specialty care?" The focus of looking at health links and the goal of health links is that they would be across the province, that they would have that kind of case management function to ensure those linkages were community-wide, not just for health, and to set guidelines for those providers to be able to understand better the complexity of how those two sectors intersect or how those services intersect to support an individual at home.

**Ms. Soo Wong:** Okay. On page 11, you talked about the steering committee. Can I get some clarification? Is this steering committee the same as the ADM committee we heard from previous witnesses before this committee? Is this the same committee?

**Ms. Catherine Brown:** Probably, yes.

**Ms. Soo Wong:** Okay. Then, given this question here and your comment, I'm just curious why in the steering committee, where the Ministry of Health is collaborating with other ministries, that the Attorney General's office is not part of it and the Ministry of Municipal Affairs and

Housing—because you identify on page 13 that you have this justice case management program. So where is the link with the AG's office, when this clearly tells us that you're working with the judicial system, but you're not collaborating with the Ministry of the Attorney General's office?

**Ms. Catherine Brown:** It's a good suggestion, and I thank you—

**Ms. Soo Wong:** I'm not seeing the link and—

**Ms. Catherine Brown:** It's a good point. I do believe municipal affairs and housing is involved. They may not be named on my list, but I believe they are part of that committee.

**Ms. Soo Wong:** Okay. I have asked consistently the witnesses before this committee that I need numbers. When I say "numbers," I mean funding. I'm not getting the funding of the various programs that the Ministry of Health and Long-Term Care is supporting—both children and youth and adults with intellectual disabilities and the various developmental disability services. So if you could provide to us some of the data, that would be really, really helpful.

Madam Chair, I don't want to hog my colleague's question. I do want to leave some questions so that the researcher can follow up on some of our questions, because I have, on almost every page—I want to be on record—every page in this presentation I have questions. So I don't want to hog all of my colleague's time.

**The Chair (Mrs. Laura Albanese):** Okay. Mr. Balkissoon.

**Mr. Bas Balkissoon:** Thank you, Madam Chair. I just want to go back to slide 6, where you have mental health and addictions. It says that there are 300 community-based mental health agencies. In the mental health review that was done by the select committee, we identified major concerns with coordination. I'm still getting people in my office where they go to the hospital and three days later they're discharged and they're on their own. I've had folks go to Ontario Shores and they're sent back home with no supports, nothing, and a couple of weeks later, they're back in again. Where is the ministry going on this particular issue, and when can we actually see some activity where that coordination comes together?

**Ms. Catherine Brown:** The ministry continues to work across the LHINs to coordinate services locally. You'll also note from the presentation that the ministry is now developing the four- to 10-year plan for mental health, which would be particularly focused on adult mental health services, and that will look to address the questions that you've raised about better integration. It's not just integration of services, but connectedness amongst services and amongst—

**Mr. Bas Balkissoon:** When are we going to hear about that, and would it have specific targets and dates?

**Ms. Catherine Brown:** I can't predict if it'll have targets and dates, but I can certainly take that suggestion back to my colleagues who are working on it. I believe it is coming out either later this year or early next year—the report, the four- to 10-year plan.

**Mr. Bas Balkissoon:** If I could go back to slide 13, as my colleague: You say that this particular initiative's available in the Central LHIN. When is it going to be available in the other LHINs across the province?

**Ms. Catherine Brown:** It is a program that they are looking at, and we'll look at the learning from that to see how we would best disseminate that across the province. So I can't speak to a date on that.

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**Mr. Bas Balkissoon:** When was this implemented?

**Ms. Catherine Brown:** I can get back to you about that as well.

**Mr. Bas Balkissoon:** And how long do we intend to assess the program before we roll it out elsewhere?

**Ms. Catherine Brown:** We'll bring that data back. I don't have that information with me.

**Mr. Bas Balkissoon:** I'll pass to my colleague.

**Ms. Mitzie Hunter:** I do want to go back to page 9. In terms of people with developmental disabilities living within long-term-care homes, are there specific assessment processes that you use before that decision is made?

**Ms. Catherine Brown:** Sorry, a decision to move someone to long-term care?

**Ms. Mitzie Hunter:** Yes.

**Ms. Catherine Brown:** Anyone who is accessing the long-term-care system would go through the same assessment process, so their health needs are assessed, their intellectual needs are assessed, and the urgency of their need for care is assessed; and then the process of selecting the homes that they would choose to be in and whether or not they're eligible to be on a waiting list, how necessary the care is—all of that. It's the same process that would be undertaken for any person who was being considered for long-term care.

**Ms. Mitzie Hunter:** Under your current work with complex needs, I believe you said that it's 5% of users of the system but two thirds of the health dollars going towards this. I'm wondering if you are looking at people with developmental disabilities under your review of this area. Is that something that has come up in your conversations?

**Ms. Catherine Brown:** I will say that a number of the dually diagnosed populations have come up. I'm not aware of particular work that is being undertaken on the DS population, but I will take that back for consideration. Certainly we're looking at people who have a variety of complex needs—health, mental health, physical, and I'm sure that part of that. But from my work on it, I don't recall people speaking to this population particularly, and I think it's something that's worthy of consideration. So I'll take it back and raise that with the table that works on it.

**The Chair (Mrs. Laura Albanese):** You have 20 seconds left.

**Ms. Mitzie Hunter:** One of the things that comes up when stakeholders talk to me about this issue is the issue of medication being provided and administered versus having time directly with a front-line worker. Do you have any comments on that?

**The Chair (Mrs. Laura Albanese):** Ms. Hunter, I'm afraid the time is up. I can't allow any more. Perhaps you can provide that answer to us, to the committee.

We appreciate your presentation and your being here today. However, we have to move swiftly, because otherwise, we won't be on time.

#### MINISTRY OF ABORIGINAL AFFAIRS

**The Chair (Mrs. Laura Albanese):** We invite up the Ministry of Aboriginal Affairs. Good afternoon, and welcome to our committee. You will have up to 30 minutes for your presentation. You don't have to take all of the 30 minutes, but up to 30 minutes will be allowed. That will be followed by questioning by all three parties. Please begin by stating your name and title anytime.

**Ms. Alison Pilla:** Thank you, Chair. Good afternoon, committee. My name is Alison Pilla. I'm an assistant deputy minister in the Ministry of Aboriginal Affairs, and I'm responsible for strategic policy and planning. My colleague is Benson Cowan. He works for me as a director responsible for social policy issues. We appreciate the time to come and present to you today. I think we're passing out some material for you as I speak.

The first thing I just wanted to draw your attention to is this large sheet that we call a placemat. This is really just to give you some context around aboriginal children and youth; the groups that we work with; some of the conditions that they experience, that they face; some of the outcomes and gaps that we notice with respect to aboriginal people, the socio-economic gap that they experience. So this is a little placemat that we use. It just kind of tracks what some indicators might be if you're growing up aboriginal in Ontario, tracking from zero to four years to 20 to 24 years, with some specific indicators around, on the social side, kids in care, child poverty, labour market, educational attainment and so on. I think you'll find that in many of the social indicators, there are varying gaps—in some cases very large gaps—in some of the outcomes for Ontario's aboriginal people as opposed to others who reside in Ontario. And on the back of the placemat, there is a listing of the references for the statistics that are on the front of the map. That's just for your information and context.

What I want to do is just take you through, at a very high level, what the Ministry of Aboriginal Affairs does in government, our mandate, some information about demographics—again, to give you a bit more of a context around aboriginal issues—and then I'm going to pass it over to my colleague to talk more specifically about developmental disabilities, services and aboriginal perspectives.

Just looking at slide 3, the Ministry of Aboriginal Affairs is a relatively new ministry for government. We were created in 2007 after the tabling of the Ipperwash report. That was one of the key recommendations, to create a Ministry of Aboriginal Affairs, so our mandate is relatively new. Our work is really to promote collaboration and coordination across government on aboriginal

policies and programs, so our work is very much horizontal, working with other ministries, such as the Ministry of Health, which was just here, on aboriginal issues, trying to coordinate program work at the government policy level.

We also are responsible for setting priorities and tracking an agenda for the Ontario government with respect to aboriginal affairs, enhancing awareness of folks who work in the Ontario public service, in government and in ministries about aboriginal issues and best practices and how to engage aboriginal people. We work with the federal government where we can, particularly to look to make the most of federal funding, because I think that many of you will understand that there is a sort of jurisdictional divide around how aboriginal people and programs are funded in Canada. I think my colleague is going to go a bit into the federal and provincial funding responsibilities there. So we work with the federal government to try align, coordinate and leverage funding for aboriginal programs.

We also try to work to help aboriginal people who live in Ontario to access programs. They may be interested in training programs in the Ministry of Training, Colleges and Universities and are wondering how those work for them and how they relate to other programming that we have, so we try to help them navigate the system, really, in terms of programs and options that are available for them. Again, it is made more complicated by this federal-provincial overlay of responsibility for aboriginal people in Canada.

One of our final goals, then, is to really encourage diversity within the public service, encouraging specifically increased representation of aboriginal people in the workforce and management and programs in the public service.

In order to achieve that, clearly we work with other ministries across government, but we also work closely with and provide funding to a number of aboriginal organizations and groups. We provide funding to aboriginal political organizations such as the Chiefs of Ontario, NAN, the Nishnawbe Aski Nation, Treaty #3, the Union of Ontario Indians—you can see the list there. But we also provide funding to other organizations that provide services to aboriginal people, including the Ontario Indian friendship centres, the Métis Nation of Ontario and others.

Clearly, Ontario has, even before the ministry was created, a significant focus on reconciliation and resolving land claims in Ontario. But besides that, in terms of program dollars, MAA really has very few program dollars. We don't fund specific programs or services. Most of our funding for programs—and I'll go into that—is really focused on capacity-building and economic development for aboriginal groups. We don't have specific program funding for health or social service programs, for example. That's a bit unlike the federal government. Their aboriginal affairs ministry holds a lot of program funding for education and for other programs for aboriginal people, but the Ministry of Aboriginal

Affairs doesn't work that way. We work with our fellow ministries to try to align their program funding for aboriginal people.

Page 4 actually sets out where our funding sits currently. You'll see that it's very much around capacity-building. We have a New Relationship Fund, which is about consultation and helps communities consult and engage with government and industry to help develop economic opportunities. We support relationship processes and policy development. As I said, we have a bit of core funding for aboriginal groups. And we have a very small capital grants program that helps aboriginal communities build, say, a business centre in the community or a local meeting site. It's very small, though; it's \$3 million a year.

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On most of our issues, our tendency is to ensure that we engage with aboriginal communities and organizations. They very often like to speak for themselves on these issues; they don't necessarily want the filter of government, even if it's an aboriginal affairs ministry, to filter out their message on things. One of the things we wanted to talk to the committee about was potentially reaching out to some of those organizations and hearing from them more directly about what the issues and challenges are on developmental services specifically. We certainly don't want to replace the voice of communities, and we appreciate the opportunity to come and talk to you today.

On page 5, it's just a little about demographics. Many people don't know that Ontario actually has the largest aboriginal population in Canada; the largest actual number of aboriginal people reside in Ontario. We have about 22% of the population in Canada. You can see the breakdown in terms of who is First Nations, Métis and Inuit in Ontario. That's how the Constitution divides out aboriginal peoples; it speaks to Indians, Métis and Inuit. As I said, Ontario has the largest population. It's about 2.4%, though, of the total population in Ontario. So although it's the largest in Canada, it's a small percentage of the Ontario population. Sometimes we find that aboriginal voices aren't necessarily always brought to the table in discussion about large programs. That's part of the role that MAA plays: trying to bring that to the table. If you look to the north, there's a large aboriginal population in northern Ontario, particularly the Far North.

In Ontario, most aboriginal people live off-reserve. When you're thinking of programs and programming availability for aboriginal people, approximately 80% live off-reserve, so they would have access to all the programs and services that you would have heard that other ministries have brought forward. It would be a different situation, perhaps, on reserve, and we can talk a bit about that. What you might find is that aboriginal groups and organizations, First Nations and Métis will say that there are some barriers to them accessing some of these off-reserve programs, that they're not necessarily culturally appropriate or that they think they should be structured in a different way. But in fact, in general, they

have access to the general services that residents have off-reserve when it comes to health and social services.

One different thing about the aboriginal population in Ontario is that it's a young population. It's much younger than the non-aboriginal population. You can see that 25% is under the age of 18, compared to 17% of the non-aboriginal population. It's growing significantly faster than the non-aboriginal population, as well: You can see 24% in that 2006 to 2011 period, compared to 5% of the non-aboriginal population. We could go into the reasons for that. Some of it relates to fertility, the number of kids that are born, but others are about identity and how you identify yourself as being aboriginal or non-aboriginal in Ontario. Since it's a young population, the median age is quite a bit lower than the average age in Ontario.

The last point I want to make before I turn it over is that we have a bit of a map at the back of the slide deck in appendix A. It's of First Nation communities in Ontario. I know it's a bit hard to read, but it just gives you a good view. When you look at the population in Ontario generally, you'll see a lot of hugging around the border—where the non-aboriginal population lives—but if you look at the First Nation communities in Ontario, it's really spread out quite evenly across Ontario, and there are a lot of northern aboriginal communities in Ontario.

I'm going to turn it over to Benson, who's going to take you through the rest of the material.

**Mr. Benson Cowan:** Thank you. So if I can start on slide 6, just by way of introduction, a lot of the conversation about the service delivery landscape in Ontario and some of the challenges is framed by the question of data with respect to aboriginal communities in the province. This is true both with respect to the on-reserve population and the off-reserve population. For various reasons, we have very little data in respect of the set of broad socio-economic indicators for aboriginal people and communities, and also more specific data with respect to specific instances of use of government services and related data.

With respect to the off-reserve population and the on-reserve population that access provincial services, the source of that data gap has to do with a current inability for most ministries to collect aboriginal-specific data. There's a range of challenges associated with that. There are some ministries that have done more work in getting ahead of managing the data question. There's still a lot of work to do, and it's sort of a central piece of some of the work that we do, as I mentioned before, working across ministries.

One of the big challenges is developing a coherent approach to encouraging self-identification. For a lot of aboriginal people, there are sometimes sensitivities with respect to identifying as aboriginal in the different ways in which they intersect with government. Where there are success stories in terms of collecting data, there has been a lot of work done at the community and individual levels in terms of encouraging self-identification.

With respect to the off-reserve issue, the data problem is complicated, not just to the extent where on-reserve

individuals access provincial services, which is often, but there is also a jurisdictional divide, where the federal government or sometimes the communities themselves are in possession of data that doesn't travel across that jurisdictional divide very easily, again, for a set of reasons.

This is often the challenge we have when it comes to assessing social policy issues with respect to aboriginal communities. We know anecdotally that aboriginal communities and populations are often the most vulnerable when it comes to certain social conditions, but it's hard for us to draw down in that data and thus hard for us to target services to meet those who are often the most vulnerable.

With respect to the issue of developmental disabilities, we can say a little about prevalence. Again, often what we do in this space is take whatever data we can identify and try to draw some big picture assumptions from it. What we do know—and this is referenced in slide 6—is that from 2008 to 2010, there was a broad First Nations regional health survey across the country. With respect to Ontario, 11% of First Nation youth reported having a learning disability, and this would be in comparison to the non-aboriginal rate in Ontario of 7%.

There's also a lot of anecdotal data and a study that we reference here from the Native Women's Association of Canada—again, this is specifically Canada-wide data—that indicate that the FASD prevalence is estimated to be up to 120 per 1,000 live births, which is a significant increase over what we would see in the non-aboriginal population across the province.

Again, with respect to the data we have, we're able to say that it's likely that there's a significant and increased prevalence of developmental disability among First Nations populations in particular, and that probably holds true across the aboriginal population in the off-reserve context as well.

With respect to slide 7, if I can take you there, we've identified through some of the literature what some of the challenges are that have been identified in this space and characterized those broadly into four areas.

The first is the issue I've just referred to, which is the sense that there is likely a high incidence of vulnerability across aboriginal communities in the province, and again especially with respect to the on-reserve population.

#### 1720

The second point that comes out in much of the literature is that there's a real paucity of aboriginal-specific programming, again especially in the on-reserve context.

The third point that is made consistently, too, is that there are significant challenges with respect to the outreach that non-aboriginal programs and services may be able to make into aboriginal communities and into aboriginal populations. There is again a range of reasons that may impact the ability for that outreach and take-up of those programs and services to be effective. There are a set of cultural barriers that aboriginal people often confront with respect to accessing non-aboriginal pro-

grams and services. There are also remoteness challenges. Also, as a consequence, often, of the lack of data, there is often a lack of understanding in the communities of the issues and available services.

The last point, which is made, I think, very effectively in a submission that Autism Ontario made in 2010 in relation to the review of the Child and Family Services Act, is that—again, this gets to the data point—the lack of data or bad data creates a lot of negative fallout consequences in which not only are you unable to identify the nature of the problem and, as I was referencing earlier, how you would then address and tailor programs and services to solve that problem, but the lack of data prevents community understanding and often presents incentives to misunderstand diagnosis or to draw connections between developmental disabilities that may be based on cultural misunderstanding or attributed to cultural differences.

I think that when we look at the range of work that has been done in this area, we see the themes, again, that I'd suggest are central around the question of how we understand the prevalence of developmental disabilities in aboriginal communities.

If I can move to slide 8, I'll speak very generally just about some of the jurisdictional complexity with respect to the delivery of programs and services on sort of the social side in Ontario.

The primary service delivery for health care is the federal government's responsibility on-reserve. That's effected primarily through a series of nursing stations and some other targeted programs that are run from the federal government.

The aboriginal people in Ontario, of course, whether they're on-reserve or off-reserve, can access primary care in the Ontario health system, and there is some extension of those primary care mechanisms on-reserve in some circumstances. There's a broader range of social services that are provided by Ontario through a funding arrangement or a set of funding arrangements with the federal government.

So the jurisdictional lines aren't always clear, but even to the extent that they are clear, the service delivery landscape can get quite complicated. Suffice to say that, as residents of Ontario, all aboriginal people can access primary health care services. If we get back to the issue of the challenges when we're dealing with on-reserve communities, through remoteness and cultural barriers to access those services, again we often see gaps in service delivery as a result of that.

If I can draw your attention to slide 9, we're trying to present here a high-level picture of what we understand some of the service delivery landscape to be with respect to developmental services. This is high-level; these are programs that are run often by independent entities who are funded by the ministries. If there are further questions about it, I can endeavour to try and find information, but I don't intend to drill down on some of the details.

There are two aboriginal-specific Community Living agencies that are on-reserve in Ontario. One of them is in

Six Nations. That's Ronatahsksats, which serves adults with developmental disabilities who live on Six Nations, and it has programs and services such as life skills, literacy, community participation, and some residential programs as well.

There is also Community Living Wikwemikong Anishinabe, which is on the Wikwemikong reserve on Manitoulin Island, and it offers a variety of programs, including a life skills and cultural program, an adult group home living program and a supported independent living program.

Now, both Wikwemikong and Six Nations are large reserves with relatively large populations, with sort of efficient economies of scale and capacity to deliver services, but that's not the case in respect of all the reserves in the province by any stretch of the imagination. They are two of the largest in size and population.

There is the Aboriginal Fetal Alcohol Spectrum Disorder and Child Nutrition Program funded by the province at approximately \$4.4 million annually, and it's offered through aboriginal organizations across the province for families with children and youth who may have been affected by alcohol before birth. In the appendix, we list the 18 different organizations that receive funding from the Ministry of Children and Youth Services that offer this program.

There is also a partnership between the Sioux Lookout First Nations Health Authority and Community Living Dryden-Sioux Lookout and Surrey Place in Toronto, which offers a variety of services to 31 First Nations in northwestern Ontario, and this includes, in the suite of services they offer: a transitional youth program that works with young adults with developmental disabilities to help them make successful transition from school to a wide range of community involvements, and they target the 16-to-24 age group; and there's a community outreach program that provides clinical services and resources via videoconferences to adults 18 years and older.

Again, it's important to keep in mind that aboriginal adults in Ontario may receive services from the approximately 370 non-aboriginal Community Living agencies, and these agencies provide a range of services, but again, we're unable to talk specifically about what the aboriginal component of that service delivery landscape looks like, because of the data questions that I referenced earlier.

If I can direct your attention to slide 10 and just give you a bit of an overview, again, in the landscape there is some federal activity, as I referenced before. Aboriginal Affairs and Northern Development Canada—the acronym is pronounced either AANC or AANDC, depending on—it hasn't really been settled into one yet, so you can choose either. It offers an income-dependent residency program that provides funding to assist in non-medical social support services to seniors and adults with chronic illnesses. It identifies children and adults as being within the service mandate, with physical and mental disabilities. The program has three major components: It has in-home care, adult foster care and institutional care.

The current funding, at least from 2007 to 2009, we understand to be about \$88.5 million per year.

There was an audit done in 2009, which indicated a few key findings. Again, this was a program that was of vital importance to First Nations communities. There is, as we referenced before, despite the lack of a clear understanding of prevalence, a significant need in First Nations communities. It also identified that in relation to that need, it was underfunded, and specifically that although the program included children's services as part of its mandate, those weren't funded as part of the program delivery in Ontario.

It was also highlighted that there were insufficient services for developmentally disabled residents, a lack of respite care, and inadequate supportive housing. AANC has noted, as of last December, that they're reviewing their funding practices and gathering information and looking to make suggested changes to their program. There's no real clarity in terms of when and where.

**1730**

The last point I'd like to make on slide 11 sort of references MAA's role in general, which is that, as a ministry, we're always somewhat reluctant to speak on behalf of specific aboriginal organizations or communities. They generally make it quite clear to us that their preference is to speak on behalf of themselves. So to the extent that those aboriginal voices, especially in the service delivery field, might be helpful, we've identified some of the key service providers who may be in contact with the affected population more directly.

There are also the political organizations, who, through a broad range of ways, advocate on behalf of their members. You might want to consider hearing from the political organizations as to how they prioritize this in terms of the suite of issues that they tend to put forward to the provincial and federal governments.

**The Chair (Mrs. Laura Albanese):** Thank you. So it goes over to Ms. DiNovo.

**Ms. Cheri DiNovo:** Thank you very much for your presentation and your honesty. I have to say, you have presented a vision of an absolute hell. It's shocking, and you've been honest about that, so I thank you for that.

I don't quite know—I mean, it's so overwhelming that it's hard to know where to start, but I guess the first question would be, how's it going, working with the feds? One of your stated mandates is to work with the federal government on providing services. How's that working?

**Ms. Alison Pilla:** It's kind of issue-specific, I would say, to some extent. The federal government has specific priorities, and where we share the same priorities, often there's opportunity to make significant progress. We do work pretty closely with the federal government, for instance, on the whole land claims piece. Those are tripartite processes.

I know the Ministry of Health has a tripartite process with the federal government and the First Nations political organizations on the health side. The First Nations organizations have identified some priorities, and they

seem to be working their way through those. Data was one of the priorities that the First Nations had identified, and addictions and mental health issues were another. So that seems to be working well.

There are other areas where there's friction between—you know, it might be between the federal government and some of our aboriginal organizations or communities about what the federal government is doing. On the Education Act, for instance, which you may have heard the federal government is looking to move forward on, there's concern about that here.

So I think it's really sort of an issue-specific basis, and it depends on what you're talking about.

**Ms. Cheri DiNovo:** I'm wondering—this is, of course, about the federal government—if they have any identifiable policy on persons with a disability and families living on-reserve, and how that impacts the provincial capabilities.

**Ms. Alison Pilla:** I'll let Benson speak to this as well. Clearly, they have a program where they've decided that they need to provide funding for developmental disabilities, and you heard that the auditor had some comments on that. It's clearly an area that they have recognized that they need to put funding towards.

Is your question: Have they made it a priority, or—

**Ms. Cheri DiNovo:** Yes, I suppose. Is the funding enough? Is it working?

**Ms. Alison Pilla:** I think there's always room for improvement. The federal government has identified some clear priorities that they want to make progress on. I think many would agree that there are multiple factors at play when you're talking about aboriginal people and the gap at the end of the day. I mean, there's the housing issue; there's education. The federal government has identified some priorities around education, land management and other things. I don't think there would be disagreement that those don't have to be addressed. At the same time, I don't think that prevents them from having a more holistic perspective on a range of priorities that need to be addressed at the same time.

If you want to add—

**Mr. Benson Cowan:** It's two things. If you look at the audit that they did of their own program, a couple of things emerge. One is that the on-reserve conditions dominate any solution, so the lack of infrastructure and inadequate housing, which is entirely a federal responsibility, makes a lot of the supports unavailable. That's a central issue that always occurs in terms of on-reserve service delivery.

The other issue—and again, this is highlighted in the audit and the federal government is looking at this—is that there is a principle of comparability that hovers over the delivery of social services in the province. The federal government is—in other respects where there is funding for social services, through the Indian Welfare Agreement, for example, which covers off four key areas of service delivery, there is a principle that the service delivery should be the same in reserves as it is elsewhere in the province. Those safeguards aren't necessarily in

place in terms of their assisted living program, and so it's a bit of a challenge in terms of how it intersects with the provincial system as well.

**Ms. Cheri DiNovo:** If it's not working—

**The Chair (Mrs. Laura Albanese):** Sorry, Ms. DiNovo. I am trying to be fair to everybody, keeping in mind that we'll be called for a vote soon—

**Ms. Cheri DiNovo:** Oh. I've got a couple of other questions.

**The Chair (Mrs. Laura Albanese):**—so I wanted to do two rounds of five minutes each, if that's okay.

**Ms. Cheri DiNovo:** Okay. Do I have time for one more question?

**The Chair (Mrs. Laura Albanese):** You have 30 seconds.

**Ms. Cheri DiNovo:** Do on-reserve children with disabilities have the opportunity to transfer outside the reserve to get the supports and the help that they need?

**Ms. Alison Pilla:** I think that children and people on-reserve always have access to provincial services off-reserve, but that creates huge challenges in terms of being separated from family and from supports. If a child goes off-reserve, can they be accompanied? It makes the whole logistics a lot more difficult, and then you're taking people out of their home environment. In some cases, when you're talking about northern Ontario, there are no roads into some of those reserves. So it's not like your nana can come visit for half an hour on Sunday. Those are huge challenges. Theoretically, there's the opportunity to do that, but at what cost, at the end of the day?

**The Chair (Mrs. Laura Albanese):** I'm going to pass it to Ms. Hunter.

**Ms. Mitzie Hunter:** Sure. Thank you so much for your presentation.

On slide 12, I'm wondering if you collect specific numbers behind the points there and if that's something that you could share with us in terms of numbers per community.

**Ms. Alison Pilla:** You mean the population? Yes, we can certainly get you—in fact, the AANDC website has information on each of the communities, including how many people are in the band and what basic services are there, like if they have a road going in or if they're hooked up to electricity. They have that information, and we can provide a link to that fairly easily.

**Ms. Mitzie Hunter:** I'm conscious of slide 11, where you talk about the voices and perspective. One of the things that we want to do as we hold hearings and give people an opportunity to speak: Is there anything that you would advise us to do so that we can really access the best information and also invite the community in to be heard during this process?

**Ms. Alison Pilla:** We're certainly willing to work with you. We could do some preliminary outreach to make sure that we understand what you want to hear and to see who best can provide you with the information you need. Certainly many of the service delivery organizations are located in or near Toronto. If you're thinking



about some on-reserve communities, you might want to think about whether there's an opportunity to go and do a visit. That would be really appreciated. I think in a lot of cases they don't always see—they're often dragged to committees versus having committees going out and seeing what's happening on the community level. We could also help with that.

**Ms. Mitzie Hunter:** Thank you.

**Ms. Soo Wong:** Thank you very much. We heard a couple of weeks ago that there is an ADM committee that meets cross-ministry. My question to you, through the Chair, is, have you been participating with this ADM committee so that there's some collaboration with other colleagues dealing with this particular file?

**Ms. Alison Pilla:** On developmental services issues?

**Ms. Soo Wong:** Yes.

**Ms. Alison Pilla:** No, I'm not part of that.

**Ms. Soo Wong:** Okay; that's the next thing.

The other piece is—

**Ms. Alison Pilla:** But I do intersect with those ministries on a regular basis.

**Ms. Soo Wong:** But you're not at the table with the other ADM colleagues. Okay.

On your big piece of paper you indicated to us that 15% of the youth in the justice system mainly represented the youth of First Nations. But in terms of that data, how come there are no programs—your page 9, I think, talks about the justice system—as they relate to developmental services in the aboriginal community?

1740

**Ms. Alison Pilla:** We certainly have information on the justice system, and services that are available in the justice system. We worked with some of our colleagues on that. I'm just not sure if they had a focus on developmental services. I'll maybe ask Benson if—

**Mr. Benson Cowan:** We can certainly inquire. I mean, that is MCSCS's area of responsibility, but we'll certainly inquire as to what's available in terms of the service delivery landscape. I'm not aware—

**Ms. Soo Wong:** I'm particularly interested in your ministry, because we know that there's a higher proportion of the First Nations community in correctional services. With respect to this particular select committee, I want to know what your ministry is doing to support those who are currently—First Nations community—in the justice system, in providing adequate services. We know that a higher proportion of the number of First Nations Ontarians are in the judicial system and the correctional services, so what is your ministry doing to support them so that they better transition when they come out into the community?

**Ms. Alison Pilla:** As I said in the introduction, we don't provide programs or services. We don't provide any of those kinds of direct supports. We do interact with First Nations and aboriginal organizations that are involved in diversion services. The friendship centres do some of that work.

We also get involved in larger initiatives that relate to the justice system generally. Justice Iacobucci recently

had a report that talked about First Nations representation on jury rolls. There was concern about the potential discrimination around how those are structured. We participate in the implementation committee on that. Then we work with ministries on individual issues that may come up.

To my recollection, we haven't been presented or dealt directly with the ministries on developmental service issues in the justice system but more the broader issues around the number of youth, the diversion opportunities, the jury roll system, those kinds of things.

**The Chair (Mrs. Laura Albanese):** Thank you. I'll have to pass it on to Ms. Elliott.

**Mrs. Christine Elliott:** Thank you very much for your presentation today. It was very helpful—very sad, but helpful, because the need is obviously so great. There's certainly a lack of services for the needs that have been identified, but even more than that, many of the needs can't be identified, for a whole variety of reasons.

We heard in the Select Committee on Mental Health and Addictions a lot of the issues around FASD, a lot of people not willing to identify that, for obvious reasons, because of the shame or embarrassment or stigma associated with admitting to using alcohol during pregnancy. But what I'd really like to ask you about are the other reasons, sort of the cultural beliefs and cultural problems, that are preventing people from coming forward.

Specifically, I would use autism as an example. Is there a cultural issue with the whole autism spectrum issue, that people are reluctant to talk about it and therefore it's hard to understand the prevalence of it and therefore understand how to treat it?

**Ms. Alison Pilla:** That would probably be a good question to put to some of the organizations that we might be able to put you in touch with, because I'd hate to sort of speak culturally for First Nations.

But having visited a number of communities and talked to a number of First Nations and aboriginal leaders—I mean, they have a different perspective on their communities, the role of everyone in their communities, and their children and how their children fit within the community itself. It's quite a different approach to caregiving when it comes to children and youth and the role of elders and the role of the community in general, and then there's a more holistic perspective on the issues.

My experience—and as I said, you should speak to aboriginal organizations—is that many First Nations and aboriginal people don't segment disease the way that we segment it. We're very used to a Western perspective: Your kidney has a problem; we'll deal with your kidney. You have hypertension, and we'll deal with that piece.

There's a much more holistic perspective on the nature of illness and what's contributing to that, and it has to do with housing and supports and emotional well-being and spiritual well-being and your access to elders and how the community interacts with each other and, you know, whether you can teach your children about the hunt and your culture. Those are all linked together, so there's less

segmentation of taking your kid to the doctor because they have this one body part that is particularly problematic. I think that's a good discussion, maybe, to have with some of the aboriginal organizations that are providing the services.

Of course, First Nations are different from Métis, and each First Nation is different, so there is not necessarily a completely common perspective on these things.

**Mrs. Christine Elliott:** Certainly I just want to get it on the record that we are intending to do some travel, if we get approval from our respective House leaders, to some on-reserve communities, and we will certainly be taking it up with the elders and the chiefs on that and consulting with some of the other organizations. It's a great suggestion, so thank you.

**Mr. Benson Cowan:** Sorry. I just wanted to add one thing.

**The Chair (Mrs. Laura Albanese):** Our bells are ringing, so please be concise.

**Mr. Benson Cowan:** There is a history with program service delivery to children in aboriginal communities

where it was historically used as a way of removing children from reserve as well. So I think there is a long-standing concern on the part of First Nations that service delivery for children is sometimes used as a way to remove children, and it still happens in some contexts. So I think there is a broader resistance, sometimes, to interacting with government in respect of seeking some of the programs and services available.

**Mrs. Christine Elliott:** Thank you so much.

**The Chair (Mrs. Laura Albanese):** Thank you very much. We apologize if this has been cut short by the imminent vote.

I just want to read something and would like one member from each party to hear me.

It is agreed that each party will provide the committee Clerk with three selections and one alternate from the list of requests to appear, to be scheduled to appear between next week and December 11, 2013. It's understood that these are the next 10 spots for our committee.

Thank you. We're adjourned until next week.

*The committee adjourned at 1747.*



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