

November 16th 2016

OCSA Response to *Developing Ontario's Dementia Strategy: Discussion Paper*

As the province's discussion paper notes, there are an estimated 228,000 Ontarians living with dementia today. It is also expected that this number will rise to 255,000 in 2020 and 430,000 by 2038.¹

The Ontario Community Support Association (OCSA) welcomes a provincial dementia strategy to ensure services are in place to support those living with dementia and their caretakers today, and to ensure needed services are in place for the future. Moreover, as it becomes increasingly likely that a national dementia strategy will also soon be developed, this is an excellent opportunity for Ontario to lead by example.

OCSA represents hundreds of non-profit agencies across the province that provide compassionate, quality home care and community support services to over one million Ontarians per year. These services are important, cost-effective measures that prevent unnecessary hospitalizations, emergency room visits, and premature institutionalization. The need for these services is growing rapidly as the population ages and more people choose to remain and receive care in their homes and communities, for as long as possible.

OCSA recommends that the province pay special attention to the following in the development of a provincial strategy:

1. The strategy must be fully funded, with new investments in supports and services.

Investments are needed to ensure patients have access to a full range of high-quality home and community support services. A strategy without adequate funding will fail to reach its goals. Funding must support a full continuum of services that address the needs of both persons living with dementia and those supporting them. These services include adult day programs, transportation services, supportive housing, and

¹ Developing Ontario's Dementia Strategy: Discussion Paper. Ministry of Health and Long-Term Care. 2016.

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respite care, among others. All of these different services are needed to provide the best possible care for people with dementia and their care partners.

Community support services such as Meals on Wheels, adult day programs, respite and transportation services allow people to safely meet their unique needs, be more independent and resilient, and live at home longer. Investments in these cost-effective services benefit the entire system as they reduce the need for more expensive hospital care, emergency room visits and delay entrance into long-term care.

One's postal code should not determine whether or not they are able to access services. An effort should be made to ensure *all* people living with dementia have access to the whole continuum of high-quality services they need, across the province. While services should be offered across the province, local programming must be tailored to meet and reflect unique needs of the communities in which they are offered.

As was highlighted by the discussion paper, in many communities there are a wide variety of services for supporting those living with dementia. However, accessing these services can be a challenge. Barriers to access can present themselves in many forms, including: waitlists, language and/or cultural barriers, a lack of transportation to service providers, and a lack of knowledge about the services offered. Barriers to access these programs also vary by community and should be addressed on a community-by-community basis. For example, the solution to address a transportation barrier would be different in Toronto than in Timmins. For a strategy to be successful, it must address all of these barriers to supports and services.

2. The strategy must address the issue of increasing caregiver distress.

The question of how best to support those who care for people with dementia is one that needs to be addressed now. Indicators tracked by Health Quality Ontario (HQO) show an alarming increase in the rates of caregiver distress.

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In their *Measuring Up 2016* report, HQO tracked an increase in caregiver distress from 21% in 2010/2011 to 35% in 2014-2015.² In addition, the 2015 report *Reality of Care* identified that “nearly half (49.2%) of patients with Alzheimer’s disease or other dementias had caregivers who were distressed.”³ This increased to 60% among caregivers with patients who exhibit difficult behaviours.

The government’s approach to caregivers must be focused on both direct supports for people living with dementia *and* services and training for their caregivers. As was highlighted in the recommendation above, investments are needed in a vast array of community support services that include both the person living with dementia and their caregiver. When a person with dementia is unable to access services or is placed on a waitlist, additional or alternative support services should be provided to their care partners. For example, a client waiting for a space in an adult day program could receive additional respite support in the interim.

The province must continue empowering care partners through training, and build on existing successful bundled payment and self- and family-directed care projects by expanding access to the many excellent caregiver training resources currently offered by providers in the home and community support sector. Proper supports for caregivers can lead to positive impacts for the rest of the healthcare system through reductions in crisis admissions to hospital, LTC homes, and Emergency Departments.

3. The strategy must include the entire community.

The strategy must address issues related to dementia that go beyond the health sector. It must encompass entire communities and aim to create dementia-friendly and healthy communities. Stigma surrounding dementia negatively impacts both people living with dementia and their caregivers. Addressing this stigma will make it easier for people to address the early signs of dementia and obtain the services they need.

To improve public awareness, stronger links between Public Health Units, service providers and research institutes should be forged to help disseminate up-to-date

² Measuring Up 2016. Health Quality Ontario. 2016. p.4.

³ Reality of Care. Health Quality Ontario. 2015. p.21

information about dementia. The province should also develop mechanisms to educate people living with dementia, their families, and their health care providers about the home and community support resources they can turn to for help.

4. The strategy must include workforce training.

Home and community care providers work tirelessly to provide high-quality care. Continuing education and skill-building based on up-to-date research ensures that the quality of service staff provides continues to improve. A 2010 study done in collaboration by OCSA, the Personal Support Network of Ontario and the Canadian Research Network for Care in the Community found that 52% of PSWs identified the need for more training on dementia. A workforce training strategy must focus on building the skills of all front-line workers, including personal support workers.

The province should work with health and education leaders to develop a set of core competencies in dementia for healthcare workers. In addition, the province needs to continue to support and strengthen frontline training initiatives such as the \$10 million annual PSW training fund.

In order to have long-term consistent capacity building Community Support Organizations should have the cost of training built into their base funding. Building training supports in the harmonized personal support funding formula would ensure there is a long-term viable funding attached to training of care providers.

Appropriate and efficient mechanisms to share knowledge and best practices between parts of the health care system are also necessary. For example, lessons learned within long-term care should be transferrable to those working in home and community care. The strategy must be supported by adequate funding to recruit and retain skilled staff.

OCSA appreciates the opportunity to provide comment on the development of a provincial dementia strategy, and would be very pleased to continue to offer input on behalf of our members in the home and community support sector going forward.