OCSA
Ontario Community Support Association

Response to *Patients First: A Proposal to Strengthen Patient-Centred Health Care in Ontario*

February 26, 2016

Introduction

About OCSA

The Ontario Community Support Association (OCSA) champions a strong, sustainable home and community support sector for all Ontarians. Our not-for-profit, community-based member agencies provide a wide variety of health and wellness services, which enable hundreds of thousands of seniors and people with disabilities to remain independent and live in their own homes and communities each year.

Members' services include in-home nursing, therapy and personal support, Meals on Wheels®, adult/Alzheimer day programs, transportation to medical appointments, respite for family caregivers, supportive housing and attendant services for persons with disabilities and many more. 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.

These cost-effective services prevent unnecessary hospitalizations, emergency room visits and premature institutionalization in long-term care facilities. The non-profit home care and community support services (CSS) sector also brings significant value to the health system. Volunteers in our sector donate an estimated 4 million hours each year.

Overall Response

The government has made an unequivocal commitment to transform the health system by delivering more health care in the community, thereby addressing equity and population health needs while reducing avoidable emergency room use, hospitalization and institutional care. Discussions regarding how to fundamentally strengthen and integrate home, community, primary and preventative care across Ontario are necessary if we are to create a system that is able to meet the population's health needs into the future.

The *Patients First* proposal focuses exclusively on four specific elements of reform. The second of these – consistent and accessible home care largely through transferring direct responsibility for service management and delivery from the CCACs to the LHINs – is a positive step – **but only if it enables a better integrated, efficient, comprehensive and accessible system of home care and community support services.** Home and community care is much broader and more diverse than CCAC services. To reach Ontario's goal of having a strong and sustainable home and community care sector, it is essential to build adequate capacity for the entire basket of home and community services, not just the more narrow clinical services provided through the CCACs.

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While there has been increased investment in home and community care overall in recent years, front-line CSS and home care agencies have not received an annual increase for operations or infrastructure for more than six years.

The gap between increased costs, due to demand and inflation, and government funding is widening, as a combined result of **serving more clients, more acute clients being discharged from hospital sooner, and increased reporting and administrative requirements from funders.**

Most historical investments in infrastructure and information and communications technologies in the sector have been directed toward the CCACs, and not the broader home care and CSS sector.

We note that the *Patients First* proposal does not contain explicit mention of community support services, and focuses primarily on services contracted through the CCACs. In order to facilitate the changes identified in the proposal, both home care and CSS require appropriate funding investments. **Current funding constraints, will limit the sector's ability to meet the growing service demands in a transformed health care system.**

The goals of the *Patients First* Proposal are only achievable with the full participation of the full range of home and community service providers.

To prepare our response to the *Patients First* proposal, OCSA surveyed home care and community support service providers in every LHIN, representing the breadth of services and populations served. We also facilitated a member consultation, during which members shared their feedback with Ministry staff directly, and contributed to this response. Our submission also reflects ongoing input from member agencies as well as clients and caregivers, including their first-hand insights about the sector's current capacity challenges and untapped potential to improve care for the population.

We have identified five key areas of greatest relevance to the sector, in order to achieve the *Patients First* proposal's goals. **At the end of the submission, OCSA proposes specific steps that are critical to the successful implementation of the *Patients First* plan.**

Five key priorities for the home care and CSS sector in relation to the *Patients First* proposal

1) **The potential negative impact of the reforms on the non-profit home and CSS sector, and the need to preserve the irreplaceable value that the non-profit sector brings to the health system.**

2) **The need to fully appreciate the implications and impact of the proposed changes on key populations that are not visible in the proposal – clients with permanent physical disabilities.**

3) **The need to ensure that the sub-LHIN areas' accountability and governance is community-driven, streamlined and not overly complex to administer.**

4) **The need to fully address the deficiencies of the current care coordination model that are highlighted in the *Bringing Care Home* and Auditor General's reports on CCACs.**

5) **The importance of greater alignment and connectivity between primary care, home care and CSS, beyond CCAC contracted and direct care services.**

1. The potential negative impact of the reforms on the non-profit home and CSS sector, and the need to preserve the irreplaceable value that the non-profit sector brings to the health system.

Unlike for-profit agencies, non-profit home care and community support service providers direct surplus funding back into services, and not shareholder profit. **Ontario's already strained health care system must maximize its resources by directing funding to frontline service provision.**

OCSA and our members are concerned that amendments to the Local Health System Integration Act, 2006 (LHSIA) and other legislation/regulations could open the door to an increased role for for-profit community support service providers, to the detriment of our clients. These changes would have three significant impacts:

- The loss volunteer services fundamental to the delivery of non-profit CSS services, resulting in an increase in costs to the health system.
- The potential loss of innovative, cost effective programs that have been created and developed by experienced not-for-profit providers in the sector.
- The potential negative impact of for-profit providers on cost and quality of care for clients.

Volunteers

Volunteers in the non-profit home care and CSS sector are a critical hidden resource that does not appear in LHIN balance sheets and budgets. Clients and families, however, are deeply aware of the importance of volunteers, whom they depend on for day-to-day services that enable them to function, such as transportation and caregiver relief.

The estimated financial value of non-profit home and CSS sector volunteers is $111 million per year. These volunteer resources would be lost if for-profit providers assumed the work currently done by not-for-profit organizations, and would need to be replaced at a significant cost to the system.

Innovative Programming

Despite limited health care funding, home and community support providers across the province are finding innovative solutions to the challenges faced by their clients. As Ontario determines how it will transform home and community care, it is critical to leverage the knowledge, successes and capabilities that already exist in home and community agencies in every part of Ontario.

For example, in 2011, the Waterloo Wellington Adult Day Program (ADP) network of providers used standardized assessments scores to demonstrate how they are able to support clients with high risk levels, medical complexities and cognitive impairment. This program, created and developed by non-profit providers, is a cost-effective alternative to long-term care that is highly valued by clients and caregivers.

For-profit providers – Less care at a higher cost

It is critical that any legislative changes not open the door to profit-sharing or remove funds which should be used to provide service for clients from the system. Moreover, the introduction of for-profit community support services delivery has begun in Ontario and could have detrimental impacts on costs and service.

For example, a for-profit, multinational meal provider has launched a home delivery meal program to seniors across southern Ontario. These meals are on average 25% higher in cost to clients, who often have limited incomes, than the same meals provided through not-for-profit Meals on Wheels® providers. Meals on Wheels® volunteers also provide important friendly visiting and client monitoring – in a for-profit model, the meal is sometimes left on the customer's doorstep without any client interaction at all. **A for-profit meal delivery service could lead to higher costs for clients, and increased social isolation.** Replacing volunteers with a paid workforce would further inflate meal costs.

The same is true for a new for-profit transportation provider seeking entry in senior transportation services in the Toronto area. This Uber-style provider is unregulated, has no driver training specific to seniors and people with disabilities, and is under no obligation to adhere to privacy standards inherent in health-related services. **Thus, it has potential to increase costs, and pose an unacceptable risk to vulnerable clients.**

As legislation changes occur, it is imperative that existing not-for-profit community support services are maintained and enhanced.

2. The need to fully appreciate the implications and impact of the proposed changes on key populations that are not visible in the *Patients First* proposal – clients with permanent physical disabilities.

The care of older adults is rightfully a key focus of the proposal. However, the needs of other sub-populations who will be significantly affected by the changes being planned are missing: clients with permanent physical and other disabilities, including brain injury, dementia and stroke.

There is a misperception that CCACs, hospitals, and LTC, with the support of primary care, are always the most appropriate providers for all individuals with highly complex needs. While this is true for many medically complex patients, it overlooks the reality that assisted living, acquired brain injury, attendant care and other independent living service agencies in the community are the main care providers for people with permanent physical and other disabilities, who have some of the most complex, resource-intensive needs.

The supportive care provided by these frontline CSS providers allows over 3000 Ontarians to live independently, as part of the community, often over their entire lifetimes. Not only do these agencies assist clients with all the essential aspects of daily life, independent living providers have extensive experience working with clients and caregivers to design and administer self-directed care to the most vulnerable in our communities. They have a superior understanding of the actual needs and wishes of clients, and an ability to be flexible and adapt to changing client needs.

In addition to improving the health and quality of life of these individuals, independent living services create substantial saving for the health system. The average cost of supporting a client

in a self-managed attendant care outreach program is **62% less** than providing similar care in a hospital. Moreover, hospitals and other facilities simply do not have the capacity to care for the increase in patient volume that would be created should these services becomes less available. This does not begin to reflect the priceless improvement to quality of life created when clients have the ability to live independently in their own cherished communities. These are critical programs, and the proposal's impact on them must be carefully considered.

OCSA fully supports the plan to closely align public health's preventative and health promotion services with the rest of the system. However, some of the broader factors that influence health outcomes, such as supportive housing, are missing from the proposal.

It is imperative that health system changes maintain and enhance these services, as we transform the home and community care system.

3. The need to ensure that the sub-LHIN areas' accountability and governance is community-driven, streamlined and not overly complex and administratively burdensome.

OCSA is concerned about the feasibility of home and community care service areas as we shift to sub-LHINs. Decentralized contracting accountability for up to 50 or more sub-LHIN entities has the potential to be extremely administratively complex and onerous.

Adding another layer of infrastructure within the existing LHIN boundaries may also add additional administrative and accessibility issues for individuals seeking home and community services. While the concept of more "local" service delivery is good, **sub-LHIN boundaries should ultimately not be defined by planners, but driven by the needs of clients and caregivers.** These sub-LHINs should be aligned with existing, natural communities that they already understand. Some of these natural communities do not necessarily fall within existing LHIN boundaries, but must still be respected and supported in terms of access to services for clients and their caregivers.

OCSA also strongly recommends that the valuable work underway to amend the Personal Support Services Regulation (Regulation- 386/99 under the Home Care and Community Services Act, 1994 relating to the Provision of Personal Support Services by Approved Agencies) continue to move forward. **Enabling clients to access personal support services via community support providers will further reduce administrative challenges and costs.**

Lead agency model

One model that has been discussed in terms of service organization is the "lead agency" model. As the Ministry has not yet fully defined what a lead agency would do to improve and support client care, we put forth the following suggestions.

In setting up for this model, it will be critical that there is a well-defined selection process and clear accountabilities set for lead agencies, which are consistently applied across all LHINs. This selection process need not assume that lead agencies must be acute care or facility-based providers.

Given their experience and knowledge of the care needs of their communities, home care and CSS providers should be considered and utilized as lead agencies. In fact, **most OCSA members recently surveyed reported that home care and CSS agencies already act in a lead agency capacity** for

initiatives in their regions, including Health Links and coordinated access initiatives for community services such as transportation, personal support and homemaking.

An example of a strong community support provider in action in this capacity is the "Supports for Daily Living" (SDL) initiative in Mississauga Halton LHIN, led by Peel Senior Link and Nucleus Independent Living. The SDL program, created by CSS providers, was developed to address patient flow issues in the hospital that contributed to high ALC rates. In partnership with CCACs, primary care and other community providers, CSS accepted high risk seniors directly from hospital, supporting them to live independently in the community and avoiding LTC placement. Outcomes are positive, with strong indicators supporting reductions in ALC, cost savings and improvements in client experience and independence.

The vast majority of OCSA members believe it is **imperative that lead agencies are non-profit organizations that have solid connections to all types of providers, and a demonstrated ability to understand client needs beyond medical and CCAC-managed services**.

OCSA members have the following comments about the lead agency model:

- Specific services for key sub-populations such as Aboriginals and Francophones should be recognized in the restructuring.
- Existing community-based partnerships within health care, with other sectors, and across sub-LHIN areas should be strengthened, rather than replaced by an entirely new lead agency or group "reinventing the wheel."

4. OCSA is concerned that the direction that the Ministry is proposing for care coordination will fail to address the major care delivery issues highlighted in the *Bringing Care Home* and Auditor General's reports.

These reports and others describe the deficiencies of the current care coordination and delivery model including fragmentation, exclusion of critical parts of the basket of services, expense, failure to match service with client need, inconsistencies, and removals and disconnections from care delivery.

The overwhelming majority of OCSA members are concerned about the current care coordination model. It is not clear how integrating CCACs and LHINs will address all of these systemic problems.

Care coordination needs fundamental reform

OCSA supports locating care coordinators within care delivery teams, such as primary care. We also support broadening coordination to cover the full continuum of home, community, primary, preventative and specialist care, tailored to the client's needs. A true population health approach, however, must enable care coordinators to link with non-health social and community services that impact health and wellbeing. **Community support and home care agencies have experience coordinating a wide range of health and non-health services for their clients and families.**

It is troubling that community support and home care agencies are not mentioned as settings in which care coordinators will be deployed. These agencies have experience coordinating a wide

range of health and wellness services for their clients and families. **More than 50% of OCSA members recently surveyed are part of care coordination solutions in their LHINs.**

Given the current structure, and certainly while we are in the midst of transforming the system, it is clear there will be a need for different levels of care coordination depending on the client's acuity, complexity and the nature of their needs. Currently, some clients who would benefit from care coordination do not receive this service. Other clients are being over-managed, leading to delays, duplication, and dissatisfaction among clients and caregivers. Some low acuity clients, for example, would experience better outcomes if they had the tools and resources to direct their own care, rather than having a care coordinator trying to do it for them.

Home care and CSS agencies have years of experience with care coordination for a range of clients, from frail older adults to clients with life-long disabilities and acquired brain injuries.

An example of community care coordination is the "Seniors Managing Independent Living Easily" (SMILE) Program in the South East LHIN. This regional program was designed in the community to improve the functional capacity of seniors living in their own homes – particularly those at high risk – and to support informal caregivers. Operated by the Victorian Order of Nurses (VON), this client-centred model utilizes care coordinators to help clients to remain at home by creating a "circle of care" around clients and caregivers. The role of the local care coordinator for the program is critical to the program's success, including the avoidance of costly LTC admissions. SMILE also supports clients who are the high users of the health system to access other needed health supports.

With the *Patients First* reforms, there is an opportunity to use experienced care coordination already in place within community support agencies to lead care coordination for clients, improving health care navigation and access to a broader range of support services.

Addressing underinvestment and building capacity in home care and CSS services

The demand for home and community care is growing every year, as agencies are being relied upon to provide more services to an older, higher-needs population, which is being discharged from hospital earlier.

Home care and community support agencies are facing severe funding constraints, which affect their ability to meet service demands. A full 86% of members say that the wage restraint or compression is currently a challenge for their agencies.

CSS and home care agencies have not received an annual increase for operations or infrastructure for more than six years. There is an increasing gap between increased costs due to demand and inflation, and available government funding. Recent funding to address PSW wages, while welcomed by the sector, has now resulted in unfunded expenditures as dollars provided do not cover all the benefits provided to PSWs.

For clients, this means reduction in services, higher fees, or the lay-off of experienced and knowledgeable staff.

These challenges come at a time when we urgently need to enhance and develop the capacity and resources in home and community. We are aware that health system funding reforms are

being considered for the home and community sector; however, it is also important that the Ministry shore up needed funding to support the transition while moving to new funding models.

Investment in technology is also critical for coordinated and high quality client care. However, the hundreds of Ontario agencies that provide home care and community support services have not received a sustained sector-wide investment in technologies. Flatlined operational budgets have further diminished agencies' ability to pursue collaborative IT solutions.

By contrast, hospitals and CCACs have received considerable targeted provincial investment in information technology in recent years and, consequently, have much more greater capacity than other parts of the system. According to its 2014-2015 Annual Report and Financial Statements for the year ending March 31, 2015, the Ontario Association of Community Care Access Centres, which manages ICT platforms and services for the CCACs, had IT expenses of $12.3 M in 2014 and $11.7 M in 2015.

We note the recent work done by the Ministry in the Health Sector Asset review last year, which found that the CSS sector had significantly fewer resources and less developed ICT systems when compared to CCACs and other parts of the health system. **Despite these formidable challenges, OCSA members are highly committed to developing their ICT capabilities.**

We support the Ministry's selection of InterRAI tools and use of InterRAI-CHA to support data collection in home and community. This evidence-based and client-centred decision support tool has been broadly implemented across the sector and should be leveraged to support care models and resource allocation.

5. The importance of greater alignment and connectivity between primary care, home care and CSS, beyond CCAC contracted and direct care services.

A critical area that is missing in the *Patients First* proposal is the need to connect primary care and *all* community-based services. To improve client experience and outcomes, the restructuring must support integration between home care, CSS and primary care.

Most OCSA members surveyed agree (20% strongly agree, 50% agree) that there are good linkages in their regions among different community-based programs, primary care and other services. These programs could be leveraged, scaled up and spread across Ontario. Examples include:

- Caredove, an online scheduling and coordination platform in use in the Waterloo Wellington LHIN, allows primary care and other providers – as well as clients – to make seamless electronic referrals to a full range of home care and CSS services in different LHINs.
- Rural health hubs bring together primary care and community care services.
- Behavioural Supports Ontario (BSO) - a multi-sector collaboration between primary care, Family Services, the Canadian Mental Health Association, the Alzheimer Society and CSS providers, for shared services.
- A HealthLinks CSS lead agency model for integrating community services and linking them with other sectors, such as primary care.
- The "HouseCalls" program, wherein primary care health teams embedded in a community support agency provide a broad range of health services seamlessly to housebound frail seniors.

Conclusions

Home and community support providers have deep roots in their communities, decades of experience, and a track record of innovation and success. Often, they have the most direct experience working with clients. **It is imperative that this extremely valuable knowledge be put to good use during health system transformation.**

OCSA members are eager to do their part, for the benefit of clients, caregivers, and all Ontarians. As a starting point, we offer the following recommendations.

Recommended steps to achieve the goals of the *Patients First* proposal

1. Ontario's already strained health care system must be maximized by directing needed resources to the frontline service providers, and not to needless administrative structures.

2. Any efficiency gained from integrating the LHIN and CCAC administrative and governance structures should be reinvested directly in frontline home and community support services budgets. This will build needed capacity, address inequities and improve consistency of services across Ontario.

3. Legislative changes to the LHSIA Act should not open the door to additional government-funded for-profit home care and CSS services.

4. Develop a more comprehensive model of care coordination services that can be delivered by a broad range of providers, including home care and CSS agencies.

5. Ensure inclusivity for all populations served – particularly those with permanent disabilities living independently in the community.

6. Leverage current assets used in home and community – such as Health Partner Gateway (HPG) and the Client Health and Related Information System (CHRIS) for the entire health system, bringing needed technology capacity to CSS and home care providers.

To truly put the client first and make community and primary care the foundation of the health care system, CSS and home care agencies must be full participants in health system transformation planning and implementation, in every LHIN.

On behalf of our members, we ask that the Ministry enable and support this contribution.