Seniors for Social Action (Ontario)

IS HOME CARE WORKING IN ONTARIO?

A REVIEW OF HOME AND COMMUNITY CARE SUPPORT SERVICES

October 2023

Seniors for Social Action (Ontario) (SSAO) is an incorporated non-profit social advocacy organization formed in March, 2020 in response to the carnage in long-term care facilities during the pandemic. It is comprised entirely of volunteers from across the province who donate countless hours advancing the objectives of aging in place and creating inclusive, welcoming communities. SSAO has produced Op Ed pieces for major newspapers, research and policy papers, editorials, letters and briefs to government, has held online educational events, engaged with the press, and formed partnerships with other like-minded organizations.

Many of its co-founders were leaders in advocating for the closure of large facilities for people with developmental disabilities decades ago. This has led to a strong organizational commitment to advocacy for the creation of non-profit in-home and community-based residential alternatives to institutions, and direct funding options to empower individuals and their families.

With over 1200 members in Ontario, SSAO has become a strong voice for a new generation of older adults.

SSAO receives no funds from any source except occasional donations from members which pays for our website, mail outs, and other administrative costs. This allows SSAO to remain an independent voice for elders in the Province of Ontario not beholden to government or private corporate funding.

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The primary researcher for this report, Patricia Spindel, Ed.D Chair, Seniors for Social Action Ontario, was assisted by co-founders, Board members, members, and key informants inside and outside of SSAO who played important roles in its creation.

No payment was received by anyone in the preparation of this report. All of the research and writing was completed by volunteers.

With special thanks to the Ontario Caregiver Coalition for their sage advice and support in the preparation of this report.

Senior Managers of Home and Community Care Support Services were invited to respond to Seniors for Social Action Ontario's questions related to the content of this report, but declined to do so.

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INTRODUCTION

Rationale For This Report

This report is being produced because increasingly elderly and disabled members of Seniors for Social Action Ontario (SSAO) are telling the leadership that they are considering Medical Assistance in Dying (MAiD). They say they are doing this because they cannot obtain the necessary supports and services to be able to age with dignity in their own homes and communities. They are choosing not to live out their full lifetimes out of a sense of despair and fear of institutionalization. Some say they are afraid of dying alone and suffering, helpless, for days because they cannot rely on in-home help. Others have tried to obtain services and supports through Home and Community Care Support Services (HCCSS) based on what they know their needs to be, but they are denied support based on those stated needs. Sometimes workers are scheduled at awkward times, some workers seem unskilled, or do not show up on time, or at all.

Those who would like to access Family Managed Care – a direct funding option offered by Home and Community Care Support Services that would allow them to arrange their own supports, say they are told they are not eligible for this program by their care coordinators.

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This report is intended to uncover the reasons why HCCSS appears unable to meet the needs of so many people and includes recommendations for improvement.

INACTION BY THE PROVINCIAL AND FEDERAL GOVERNMENTS

It is of deep concern to SSAO that the provincial and federal governments have not funded an appropriate range of in-home and non-profit community-based residential services to allow people to age with dignity. "Between March 1, 2020, and August 15, 2021, over 56,000 residents and 22,000 staff in Canada's LTC and retirement homes were infected with COVID-19, resulting in more than 14,000 deaths among staff and residents…. In Canada, LTC residents accounted for 3% of all COVID-19 cases and 43% of COVID-19 deaths" (Canadian Institute for Health Information, 2021). This was one of the highest death rates.in the world - with little to no subsequent action having been taken. It should be clear to our elected officials by now that institutions are not safe for elders or people with disabilities.

Aside from creating federal standards that many consider unenforceable and a symbolic gesture intended to improve institutions that many feel cannot be improved, little to nothing has been done to help people to age where they want to be – in their own homes and communities.

Ontario has responded by building even more institutions in which to warehouse elders and people with disabilities rather than creating a vigorous system of in-home and community-based support that is publicly accountable. This government has provided new funding to institutions at a rate six times higher than they are providing new funding to Home Care (Ontario Government, April and November, 2022). It should not be surprising therefore, that so many elders are unjustifiably being driven into institutions. The Ministry of Health's own data shows that 69% of individuals in these facilities have no significant disabilities (Ontario Ministry of Health Continuing Care Reporting System, 2020/21, Q2 data cut).

All levels of government have known for a long time that Baby Boomers – a very large generation – are aging. But all seem wholly unprepared for this.

HOME AND COMMUNITY CARE SUPPORT SERVICES (HCCSS): A SYSTEM IN DISARRAY

This report will show that HCCSS, the latest iteration in the evolution of the Ontario government's attempts to provide in-home and community-based support services is in disarray. It suffers from:

- Being under-funded and under-resourced. All of its 14 offices were in administrative deficit as of 2022 according to its CEO, and under-resourced, which may be causing service rationing and an inability to respond adequately to the needs of service users;
- Clumsy handover of responsibilities from CCAC's to LHIN's and on to HCCSS;
- A service philosophy and culture that is staff-centered, thereby failing to empower service users and their families;
- Having a system of service contractors, many of whom are for-profit, that are only able to meet clients' needs 50% of the time;
- A human resources system that requires minimal qualifications for positions where staff exercise considerable control over service user's lives, and where there is little to no public information concerning additional training and supervisory support available through HCCSS;
- A lack of effective representation of service users and their advocates in decision making capacities on the HCCSS Board;
- A "community engagement" approach that is not aligned with the usual principles of community engagement - one that is staff-centered, restricted, and controlling and fails to provide a mechanism for incorporation of information concerning systemic issues from advocacy organizations representing service users;
- A complaints management system that is failing;

- A middle and senior management structure that lacks an effective management information system, and appears cut off from clients and what they are experiencing;
- A data gathering, analysis, and information system that does not meet provincial requirements for adequate protection of information or provide information that should be available to the public in spite of HCCSS's claims of being transparent.

Methodology

SSAO, in addition to hearing from its members directly via e-mail and phone, also surveyed its membership to gather information about how well HCCSS is meeting their needs and those of family caregivers. HCCSS Client Survey results are available in a separate report.

SSAO conducted a review of documentary information concerning HCCSS which is publicly available on its website and elsewhere, and submitted a list of questions to HCCSS senior management. HCCSS management has declined to respond to these questions or to have input into this report. The questions submitted to HCCSS and its response are included as Appendix A.

Some interviews were conducted with key informants who had considerable knowledge of the HCCSS system.

SSAO also reviewed press reports concerning home care, and reports by organizations with an interest in home care.

ELDERS WANT HELP, BUT IT IS NOT ALWAYS THERE

95% of those over age 45 in Canada have been very clear in stating that they wish to remain in their own homes and communities as they age (Ipsos, 2022). Most are unsure of whether or not they can, because few can afford the cost of a personal support worker if they try to arrange one privately. Not only this generation of elders, but the next, seem concerned about whether or not in-home care will be available to them.

It is reported to provide a range of services including: nutritional counseling, speech therapy, occupational and physiotherapy, nursing, social work, personal support, medical supplies and equipment, and care coordination. But does it actually meet the needs of its clientele?

Home and Community Care Support Services (HCCSS) is Ontario's publicly funded Home Care system. HCCSS is comprised of 14 organizations across Ontario that "co-ordinate in-home and community-based care for thousands of patients across the province every day" (HCCSS, 2023). It is reported to provide a range of services including: nutritional counseling, speech therapy, occupational and physiotherapy, nursing, social work, personal support, medical supplies and equipment, and care coordination. But does it actually meet the needs of its clientele?

Inadequate Funding and Resources from the Ministry of Health

According to the HCCSS Business Plan, 8900 or more staff serve more than 640,000 clients of all ages each year. Of these 27,270 end up institutionalized, although the HCCSS website places this number higher at 28,700. Also provided are 26,900 or more nursing visits, 5600 or more therapy visits, and 100,000 or more hours of personal support care (HCCSS, 2023).

HCCSS receives a total budget of $3.4 billion, and works with more than 150 service providers, "via 400 contracts which includes services such as nursing and personal support, as well as hospices and medical vendors" (HCCSS About Us, 2023G).

The Federal government's commitment to Ontario for the fiscal year 2023/24 for home and community care is $232,871,112 (Government of Canada, 2023).

On April 25, 2022, the Ontario government announced that it was investing $1 billion more in Home Care over three years to 2025 (Ontario Government, 2022), approximately $334 million a year.

This appears to mean that much of this is Federal funding. Yet as of February 16, 2023 home care services were saying publicly that just a fraction of that funding had actually been paid out "leaving the faltering system that provides care to people in their homes and in the community teetering on the brink of collapse" (Payne, 2023). This meant that agencies were not expanding services, but cutting them.

Care Watch Ontario, in its pre-budget submission was asking for immediate investments including a strategic allocation of $425 million that had been previously announced in the 2022 Ontario budget, but apparently not paid out. It would have added 2.72 million hours of home care services. Care Watch Ontario also asked for an additional $212 million to meet growing client needs and tackle inflation as well as support the development of more innovative approaches of benefit to clients and the health care system as a whole (Care Watch, 2023).

According to the Financial Accountability Office, government had planned to spend $3.73 billion for home care in 2022/23, but actually spent $3.59 billion - $14 million short of its target.

The global spending on community and home-based supports also falls far short of what the government is spending to institutionalize people. The average annual growth spending on long-term care institutions was 12.9%, and only 5.7% for community-based programs.

"The FAO projects community programs spending will grow at an average annual rate of 5.1 per cent from 2021-22 to 2027-28.... driven primarily by increased spending in home care and community support services" yet "despite these investments, the FAO now

projects a modest decline in the number of nursing and personal support hours per Ontarian aged 65 and over, from 20.6 hours in 2019-20 to 19.4 hours in 2025-26. This is a slight deterioration compared to the FAO's March 2023 forecast which projected that the Province's investments would maintain 2019-20 levels of home care services per Ontarian aged 65 and over" (Financial Accountability Office of Ontario, 2023).

What this shows is that the Ontario government's spending is nowhere near keeping up with the demand of a large, aging demographic when it comes to supporting elders' ability to age at home.

The CEO of HCCSS in an Attestation dated June, 2022 states:

> ***"All HCCSSs have internal Administration budgets that are deficits for fiscal year 2022/23 and were required to arbitrarily reduce line items to submit a balanced budget for the Annual Business Plan. HCCSS will work closely with the Ministry during the fiscal year to develop plans that will achieve balanced budgets by fiscal year end and have submitted requests for additional funding. The ability to balance Administration budgets without additional funding will be challenging and require aggressive cost containment strategies."*** (Martineau, 2022)

THE CLIENT'S JOURNEY: A CONVOLUTED, DISEMPOWERING PROCESS

Step One: Assessment

The first hurdle for a service user is to be assessed as requiring Home Care. This is not a person-centered system as is claimed, but a staff-centered system.

> *"The caregivers should have more power to determine the care they need and be able to manage it. Also we only get 30 minutes of care which is totally insufficient. It's only because I am here that my dad hadn't taken a fall or deteriorated." (HCCSS Client Survey respondent)*

Whether or not an individual believes they require in-home care, it is an "assessor" who determines whether or not they will receive it. Power is centered in the hands of the "assessor", not the person needing care. It is this power imbalance that creates serious accessibility issues for many seeking the services of HCCSS. SSAO members are reporting a discrepancy in what assessors believe they require and what they believe their needs to be. Sometimes services are simply not available at all.

> ***"The caregivers should have more power to determine the care they need and be able to manage it. Also we only get 30 minutes of care which is totally insufficient. It's only because I am here that my dad hadn't taken a fall or deteriorated."*** (HCCSS Client Survey respondent)

> ***"For me, the worst part was that there wasn't any service available in a timely fashion. For example, when I asked about getting in home help I was told that we could be put on a waiting list. When I asked how long that might take, I was told "about a year." When I replied that he probably doesn't have a year, they said that there was nothing to be done."*** (HCCSS Client Survey respondent)

Those who need help, but are found not to qualify for it, or who do not receive help at the level they require it through HCCSS are on their own. Some have advised SSAO that they are considering MAID.

Step Two: Care Coordination

If elders and people with disabilities manage to successfully jump through the first hoop and are found to be eligible for home care, they will be assigned a "care coordinator".

The care coordinator's job is to work with individuals to determine "which services would best support [their] health and well-being – at home or in the community" (HCCSS, 2023).

The care coordinator may be a nurse, social worker, occupational therapist, physiotherapist, or speech therapist. When asked, no information was provided by HCCSS on whether or not care coordinators receive case management training and supervision to prepare them for this role. Survey respondents are reporting that while their care coordinators appear empathic they are not really equipped to assist them to properly navigate the system and obtain the services and supports they need. There also appears to be considerable turnover in care coordinators.

> ***"Contact person at HCCSS seems to change pretty regularly. I wonder why. They are note takers and a referral service but not a very good one. If you know what you need and want and where you want it from they are helpful, but if you need help evaluating what you need and where the best place to go for that help is…not so useful."*** (HCCSS Client Survey respondent)

Care coordinators liaise between individuals receiving care and hospitals, family physicians, communities, schools, and others to "facilitate a seamless, coordinated flow of information between patients, families, and care team members." They develop an "individualized care plan" said to optimize peoples' health and independence, irrespective of the person's circumstances (HCCSS, 2023b). The care plan is based on the person's "assessed needs" as determined by an assessor, not on what they consider their needs to be. There is no readily available public information on the criteria assessors use to determine the needs of individuals. HCCSS was asked about this but no response was provided.

It appears care coordinators are not aware of HCCSS's own criteria for families accessing direct funding through Family Managed Home Care. Access seems to vary depending upon which of the 14 offices are contacted. The eligibility requirements for this program

are also discriminatory based on age - geared towards younger people, and restricted for older adults unless they are in "extraordinary circumstances" (HCCSS, 2023e).

Therein lies the second hurdle. It is not the person who is in charge of how much care they receive, what type, when, or how, it is the "assessor" and the "care coordinator" who decide this, thereby removing control from clients and those who support them. Not all clients appear to be provided with the same information concerning care options. Their plan is not actually "individualized" - based on the individuals' stated needs. It is based on what the assessor and care coordinator consider those needs to be.

This creates a second power imbalance. Elders and people with disabilities are subject to the decisions that assessors and care coordinators make. The underlying service principle appears to be that professionals hired by HCCSS know best what a person needs rather than the person themselves. This reflects a paternalistic "professional knows best" approach to needs assessment and subsequent care provision that is disempowering for individuals who are already vulnerable.

This creates a second power imbalance. Elders and people with disabilities are subject to the decisions that assessors and care coordinators make.

So not a person-directed system of support wherein the service recipient makes the decisions concerning their own care because they know best what those care needs are. It is a rationed system of care, where the service recipient may have some input, but it is professionals, with varying knowledge levels and skill sets who determine the type and amount of care the individual receives.

Professional Qualifications

SSAO inquired about the qualifications of the professional staff who conduct the assessments, but HCCSS declined to respond, so it is not possible to know what qualifications they have to determine whether or not someone is eligible for HCCSS services.

Care Coordinators

A review of job postings shows that some care coordinator positions are temporary. In general, care coordinators are required to be a member in good standing with the professional college that governs each of the professionals eligible for this role, have 1+ year of recent experience in community health or a related field, knowledge of community resources and the health care delivery system, have "excellent interpersonal, communication, assessment, problem-solving, and decision-making skills, effective time management, prioritization and organizational skills, and the ability to work independently and co-operatively in a busy multi-disciplinary environment" . Care coordinators must also be able to complete documentation, reports and forms, have a valid driver's license, be proficient in a Windows environment and be vaccinated against COVID.

So 1+ year of experience to be a care coordinator with control over people's lives and whether or not they receive the care they need.

Even Operations Leads are only required to have 3+ years of experience in "a community health care setting". Are long-term care facilities considered "community health settings"?

SSAO also inquired about whether or not care coordinators receive training as case managers, but HCCSS declined to respond.

This is not a system that empowers its users. It is one where its users have to try to convince their "assessors" and "care coordinators" who have varying levels of skills, knowledge, and experience, to organize the type and amount of care that they require. This can be a frustrating experience for services users who already feel vulnerable because of illness and physical and/or cognitive losses.

The optics are of a system plagued by frustration and failure for many of HCCSS's clients. The principles upon which it is based are flawed and represent power imbalances between professionals and those they serve. Disempowering service users and not meeting their needs sets them up for admission to hospitals and long-term care institutions. It can also create despair, leading their clients to consider MAID.

Step Three: Service Booking

Team assistants within HCCSS book client visits, provide administrative support and aid to in-home, placement, and office Care Coordinators, "act as a liaison for patients and service providers, Care Coordinators, and other stakeholders in order to maintain accurate and current patient records using available technology, including the patient database" communicating with individuals receiving care and other professionals as needed.

Team assistants must have Grade 12 and a diploma from a community college in business or office administration, or a medical diploma with 2 years of related experience - experience in a health care environment being an asset. They have to be able to communicate orally and in writing with a sound knowledge of English, be able to spell, punctuate, and otherwise have reasonable grammar skills. Windows and Microsoft applications knowledge is required and experience with patient databases and other applications used by HCCSS being assets. They also have to be organized and able to prioritize and maintain confidentiality and exercise discretion and good judgement, as well as attend work regularly.

Herein lies the third hurdle and another stage of service user disempowerment. Individuals can state what their preferences are for when they receive care, but there is no guarantee that they will receive it when they ask for it, and no guarantee that the person "booked" will actually arrive on time or at all.

It is an approach that responds to the needs of the system, not the service user. It empowers neither the team assistants, nor the clients, but it does empower the contracted service providers who control what resources they have available and when in spite of having been contracted to provide care.

Survey results show an inconsistent system of bookings where clients receive care when they need it about half the time.

> ***"Sometimes care was arranged with one/two providers who kept a consistent schedule, but there were a number of times when we needed to "chase down" the care and a few times the provider didn't show up at all without us being informed."*** (HCCSS Client Survey respondent)
>
> ***"The agency created the schedule and our family had to conform to it."*** (HCCSS Client Survey respondent)
>
> ***"Except the day the worker showed up drunk"*** (HCCSS Client Survey respondent)

"The agency created the schedule and our family had to conform to it." (HCCSS Client Survey respondent)

A reasonable question in light of these comments is, who in the HCCSS system checks in with clients to see what quality and quantity of services they are actually receiving? What is HCCSS's quality assurance process and does it include direct client input?

The lack of reliability and steady workers in this system has caused some SSAO members to report considering MAID for fear of being left for long periods suffering and possibly dying without anyone finding them for days.

Step 4: Dealing with Service Contractors

Once care is arranged and workers begin appearing in people's homes, clients come face to face with the agency workers hired by the agencies and companies with which HCCSS contracts, many of which are for-profit providers.

There is no readily available public information on how HCCSS monitors the type, reliability, and quality of care its "contractors" provide. The public has no way of knowing whether or not contractors are paid even if a care provider does not show up, thereby possibly incentivizing for-profits to double book staff or convince clients to cancel a visit because they will be paid anyway. There is some evidence that this does occur, especially if a worker calls a client with dementia who does not understand who is calling, and does not "consent" to the visit.

There appears to be no publicly available information about a system of sanctions for those contractors that are not living up to the requirements of their contracts or are finding ways to evade their responsibilities.

In response to a CBC documentary on the home care crisis, Home Care Ontario issued this statement:

> "***Before the pandemic, our acceptance rate for nursing referrals hovered at around 95%. At last count, on February 10th, they were at 54.7% province-wide. That means home care providers are unable to effectively serve five out of every 10 people who require nursing care. Meanwhile, the acceptance rates for PSW referrals have fallen to only 40%."*** (CBC News, 2022).

This is obvious evidence that contracted providers are failing clients and are not able to attract the staff required to provide care.

These examples provide a glimpse of the impact of HCCSS's service system on some service users.

EXAMPLE 1

Ms C is a highly qualified nursing professional who required a specified number of hours of personal care per week. She was feeling a sense of despair. She was well aware of what she required, yet an assessor would not agree to it, causing her to have to plead with HCCSS and finally have her situation brought to the attention of senior management with the support of SSAO before her concerns were reviewed. Even then, she reported not receiving the care she had originally requested.

If a highly qualified nursing professional has this difficult a time convincing an assessor and a care coordinator about what care she requires and when, what chance do ordinary people without this experience and knowledge have?

EXAMPLE 2

Mrs T has begun to require more care as she gets older. Her family provides the bulk of that care but occasionally they could use a break, but are unable to take one. The problem is that they are never sure if an HCCSS care provider will show up, whether or not they will be competent, or they will have to train yet another worker in the constant revolving door of workers, or be there to supervise, thereby not getting a break.

HCCSS "services" have been a source of stress for this family rather than a source of support.

EXAMPLE 3

Mrs R requires considerable care and supervision. Her daughter provides much of this, and has suffered financially and emotionally as a result. She could no longer leave her mother in a long-term care institution where she worried about her care and safety.

Care provided by HCCSS has been spotty at best, with care providers not having the knowledge or skills to properly care for Mrs. R. This has led to repeated confrontations

between the daughter and HCCSS adding to her stress, and likely to the stress levels of staff and managers at HCCSS.

Several issues arise in this example including the reliability of HCCSS services, the qualifications, skills, and knowledge of the staff being hired, and the skill levels of care coordinators and managers in handling conflict with clients and their advocates.

A WELL-INTENTIONED SYSTEM OF CARE THAT IS FAILING

Inconsistent Response to Concerns

Individuals have little recourse but to go back to the care coordinator or team assistant if the person supposed to be providing care does not show up, or does not show up on time, or is not skilled. Whether or not there is effective follow-up and reparation made seems to depend on the diligence and level of caring of the coordinator and/or team assistant. This can be inconsistent across the 14 area offices.

Lack of Public Information Concerning Training and Supervision of Staff

There is no public information about the kinds of training and supervisory support care coordinators, team assistants, and front-line staff of HCCSS receive, or whether there is training available with standardized learning objectives and qualified trainers. Effective in-service training can play a part in establishing clear expectations for staff. There is concern that information is not provided to staff taking over care of clients from other staff, resulting in a revolving door of workers having to be constantly retrained by family caregivers.

> ***"Providers have been good, some are excellent. But providers change … therefore, one needs often to train or orient the workers to personal needs/ process."*** (HCCSS Client Survey respondent).

When SSAO requested information about staff qualifications, training, and job descriptions, no response was provided.

No Effective System of Monitoring Quality, Amount, and Reliability of Care Provision: A Problem of Inadequate Funding and Resources by the Ministry of Health

There also appears to be no effective system of monitoring actual care provision. Unlike in long-term care facilities, there are no publicly available inspection reports that detail to what extent the companies, agencies, and organizations with which HCCSS contracts to provide care actually provide it, and what its quality is. The public has no idea of what to expect when approaching one of the 14 HCCSS offices for assistance.

There also appears to be no effective system of monitoring actual care provision.

SSAO members regularly report service rationing, staff not staying for their allotted time, staff not showing up or not showing up on time even in critical situations where not to provide care on time would cause harm to a client, staff not being qualified for their roles, and in one case a survey respondent reported staff showing up impaired.

The following comments were made in the Seniors for Social Action Ontario's HCCSS Client Survey:

- Never the same person always late.
- Over the course of 7 months the service was inconsistent, and often non existent. I did appreciate the funding, the physio and occupational therapists, but the PSW and nursing was not up to standard.
- No flexibility allowed.
- Services when they arrived were adequate… but no shows were problematic
- Lack of prompt communications with no evidence of holding contracted agencies to account in spite of numerous reports re: concerns - follow-up feedback poor.
- Poor response to client's actual needs.
- There is no consistency, different people show up. Caregivers seem to be pressed for time and have little nursing training.
- Consistency of care and accommodating clients' needs is poor.

The CEO of HCCSS may have provided an explanation for the rationing of services in an Attestation filed in June, 2022.

> ***"All HCCSSs have internal Administration budgets that are deficits for fiscal year 2022/23 and were required to arbitrarily reduce line items to submit a balanced budget for the Annual Business Plan. HCCSS will work closely with the Ministry during the fiscal year to develop plans that will achieve balanced budgets by fiscal year end and have submitted requests for additional funding. The ability to balance Administration budgets without additional funding will be challenging and require aggressive cost containment strategies."*** (Martineau, 2022).

Administration budgets in deficit would require aggressive cost containment strategies. Could this be part of the reason for HCCSS service rationing?

The public has no way of knowing.

A USER UNFRIENDLY COMPLAINTS RESOLUTION PROCESS: STEPS ILL AND DISABLED PEOPLE ARE REQUIRED TO TAKE TO ATTEMPT TO HAVE THEIR CONCERNS ADDRESSED

Of all the areas covered in the HCCSS Client Survey, the complaints process was the most problematic. Service users either do not know about the complaints process, or report that it did not address their concerns.

HCCSS service users also appear not to be routinely given contact information for Patient Relations/Quality Teams in the area offices, and they are not mentioned on the HCCSS website as even having a role in the complaints process. Most service users are surprised to learn that such entities exist within HCCSS.

Most service users also do not know that they can contact the Long-Term Care Action Line to make a complaint about HCCSS as well as long-term care institutions.

They are not routinely given the contact information for the Patient Ombudsman.

Providing this information to those receiving care and their supporters at the beginning of the process would likely inject some accountability.

What Complaints Will HCCSS Handle?

In a bit of an unusual twist, HCCSS outlines, on its website, the kinds of complaints it will, and by elimination, those it will not accept. It will accept complaints concerning:

- A decision that someone is ineligible for services;
- A decision not to provide a particular HCCSS service from the individual's care plan;
- A decision concerning the amount of HCCSS services the individual will receive;
- A decision to terminate provision of an HCCSS service.

What if the person who shows up to provide care is rude, steals, or worse, is abusive?

What if someone assigned to provide care does not show up at all?

In a bit of an unusual twist, HCCSS outlines on its website the kinds of complaints it will, and by elimination, those it will not accept.

What if the person who shows up does not seem to know what they are doing?

What if the family caregiver has to keep training a revolving door of workers because those providing care are never the same, and have varying levels of skill and knowledge?

What if HCCSS decides when it will provide care, and it is not based on the needs of the person or their family caregiver?

What if someone wants to access the direct funding program – Family Managed Home Care - and direct their own care, and are refused access by the assessor and care

coordinator, and told they do not meet the currently restrictive and discriminatory eligibility requirements of this program?

A lot of important "what ifs" that are seemingly not covered by the HCCSS Complaints Process as outlined on its website.

Steps outlined on the HCCSS website that are required for service users to have their concerns addressed reflect a culture of control by staff and a largely disempowering process for service users.

A Staff Centered Complaints System

Clients' concerns are to be "reviewed and assessed for resolution options" by staff.

This gives the appearance of the service user's proposed resolution of the complaint or concern not being HCCSS's priority, but rather staff's review and assessment of the individual's complaint being the priority. This attitude to complaint resolution disempowers the individual and diminishes their ability to control their own lives.

It also sets up HCCSS management and staff for greater conflict with those to whom they are providing care than might occur if a different, more user friendly approach to complaint management and resolution was used.

Since aging comes with many losses, this additional loss of control at a time of life when individuals are already feeling exceedingly vulnerable is the worst possible approach to "complaint management".

> ***"I felt that HCCSS only presented solutions for problems at hand- not necessarily in preparation for what's to come. They only seem to truly respond at a quicker pace in times of crisis."*** (HCCSS Client Survey Respondent)

"Never received full amount of support to which we were entitled. Had to resort to very poorly run private agencies to add to hours - never worked" (HCCSS Client Survey Respondent)

> ***"Never received full amount of support to which we were entitled. Had to resort to very poorly run private agencies to add to hours - never worked"*** (HCCSS Client Survey Respondent)

Steps in the Complaints Process

The HCCSS complaints process outlines the steps the disabled or ill person must take to attempt to have their most basic concerns rectified.

STEP ONE: Contact their care coordinator - if they are available.

STEP TWO: If the complaint is not resolved at this level, the person must ask the care coordinator to speak to their manager. The client appears not to be empowered to speak to the manager directly. The service user's communication with the manager is filtered through their care coordinator with no guarantee of the accuracy of that information

transmission. This gives the appearance that managers do not wish to speak directly with those receiving care with respect to their concerns. Are there too many concerns being brought, and if so, what is being done to systemically correct repeat problems? Speaking directly to service users could be a tool to assist managers in addressing any systemic issues, professional skill concerns, attitudinal problems, and other issues, yet managers appear to be cut off from this direct contact, and all information comes to them through the care coordinators.

This, again, creates a power imbalance between care coordinators and those they serve, and further disempowers service users.

STEP THREE: If the manager, after speaking with the care coordinator, does not effectively address the problem, the disabled or ill elder must request a formal review as outlined by the manager – possibly one of the people being complained about. This represents a conflict of interest.

STEP FOUR: There is no public information on the HCCSS website about what constitutes a formal review, what the process is, and who conducts it. If the complaint is not resolved through a formal review, the decision can be appealed to the Health Services Appeal and Review Board - if it involves eligibility for service or the type and amount of service received or discontinued. The myriad other concerns that can arise appear unable to be addressed at this level.

At no point does it appear that an individual who makes a complaint will be given a written reason for their complaint not being addressed. How is one to appeal if no written decision regarding a complaint is provided?

What is notable throughout is that there appears to be no involvement in the complaint process of Patient Relations or Quality Assurance, even though direct service user feedback should be important to both.

Ill and disabled people are expected to undertake the complaints process themselves or convince a friend or family member to do it. This reflects a stunning lack of understanding of the situations of most individuals who receive care. Many cannot get themselves out of bed, or complete basic activities of daily living, or have the cognitive abilities to understand the process, much less follow a formal complaint procedure as outlined by HCCSS.

These are the individuals who are also most at risk if care providers do not show up, care is substandard, or they are not receiving enough assistance.

Management Oversight of the Complaints Process

Senior management staff do visit area offices, but it is not known if they randomly choose client files and also visit clients while there to obtain information about the client experience.

SSAO posed this question to HCCSS senior management but did not receive a response.

Asking to review areas of conflict between HCCSS staff and service users on a regular basis would be helpful in determining to what extent internal and external resources are being applied in order to resolve complaints, and effective steps are being taken to ensure clients are receiving the assistance they need.

An effective management information system would be helpful for middle and senior HCCSS managers to be able to identify systemic issues affecting clients and staff, but none apparently exists.

Information to allow the public to determine to what extent HCCSS is effectively providing services and supports to its clientele is apparently also not available since answers to SSAO's questions were not forthcoming.

In Attestations for the periods January 1 – March 31, 2022 and April 1 – June 30, 2022 the CEO of HCCSS stated:

> ***"HCCSS organizations have not analyzed their data and have not applied the principles in the International Open Data Charter in preparation to release data as a result of resourcing challenges and other provincial priorities.***
>
> ***There is no work underway to address this exception due to resourcing challenges and other provincial priorities. However, HCCSS ensures that they respond to data requests from the public in a timely manner"*** (Martineau, 2022).

This Attestation provides a possible explanation of why the public cannot seem to obtain information from HCCSS in spite of its claim that it is transparent and responds quickly to public requests for information. Again, it appears that "resourcing challenges" are the reason, and that responsibility lies with the Ministry of Health.

A COMMUNITY ENGAGEMENT PROCESS THAT DOES NOT ENGAGE INFORMED ADVOCATES REPRESENTING SERVICE USERS

A Staff-Directed and Controlled Engagement Process

HCCSS's community of "advisors" are invited to take part in committees, focus groups, material reviews, and surveys (HCCSS, 2023f). This "engagement" process is consultation-based and not a partnership where consumers are empowered to have a role in directing the policies and practices of the organization or even in formulating questions to be asked.

Staff ask questions of advisors concerning the issues that staff feel are important and tend not to look for other feedback that does not address these specific questions. This in no way meets the criteria of an effective or collaborative community engagement process.

The University of New Mexico's Community Engagement toolkit places empowerment at the centre of any community engagement process (University of New Mexico, 2022). It points out that empowerment of a community of interest, in this case, HCCSS service users, cannot "simply be brought about. Instead, through establishing trust, being flexible, and acting with respect and intentionality, conditions can be facilitated which allow communities to become empowered. Communities must lead and have ownership of the engagement process, which requires disruption of pre-existing power structures."

HCCSS advisors do not "lead". They follow direction from staff. The process is not flexible. It is determined and run by staff who give direction to advisors, yet it is touted as "engagement" in HCCSS's Business Plan and public relations materials.

EXAMPLE 4:

When an "advisor" attempted to incorporate feedback from Seniors for Social Action Ontario, of which he is a member during the "engagement process" it created a problem that caused the head of community engagement to contact the Chair of SSAO without the knowledge or involvement of the advisor. The advisor was understandably upset to learn of this.

This example illustrates that the HCCSS community engagement process does not allow for input from informed advisors who are aware of a broad range of service user concerns, and instead sees this kind of input as problematic. Problematizing this kind of input does not demonstrate flexibility, nor does it show respect for advisors' knowledge, nor does it promote service user empowerment.

The process for developing the Community Engagement Framework itself outlined on HCCSS's website provides the first clue as to why this process is staff-directed.

> ***"Over a two-month period from April to May 2022, the Steering Committee, comprised of staff, patients, families and caregivers, heard from 67 advisors, 77 staff, 25 leaders and 10 community partners – all of whom provided valuable insight to help define a vision for engagement at Home and Community Care Support Services" (***HCCSS, 2023f).

Nowhere is it stated that the Steering Committee had done any prior community-based research into what constitutes effective community engagement in order to inform their decisions.

The professionals heard from outnumbered the "advisors" by almost two to one. It is therefore predictable that the community engagement process would not be as engaging as it could be.

No mechanism exists for advocacy organizations representing clients, caregivers, and other service users to provide valuable input with respect to systemic concerns and have them addressed in a collaborative fashion.

No mechanism exists for advocacy organizations representing clients, caregivers, and other service users to provide valuable input with respect to systemic concerns and have

them addressed in a collaborative fashion. Even SSAO's attempt to engage senior managers in providing information for this report was declined. HCCSS appears to see community engagement as a one-way street, where advisors are asked questions drafted by staff, and must stick to providing input only on those questions, but questions posed by SSAO in its advocacy role for HCCSS service users receives no response from senior managers of HCCSS.

There is no public messaging about how input received from advisors dovetails with quality assurance processes and patient relations within HCCSS, and whether or not there is an effective system of follow-up when concerns are raised.

Community Engagement Medical Model Style

The HCCSS Community Engagement Framework also relies upon the medical model of community engagement outlined in Ontario's Patient Engagement Framework (Health Quality Ontario, n.d.) and the Carman Framework developed by Kristin L. Carman et al in 2013.

It is perplexing that an agency providing "home and community care and support services" would rely on a medical model approach to community engagement rather than a community-based one. Service users across the health spectrum are aware of the hype being promoted by various health care organizations concerning their attempts to engage them, however, in light of the state of health care in Ontario, and the contents of this report concerning HCCSS, there appears to be little evidence that service users' concerns have actually been incorporated to change health care policies and practices and make them more user friendly, accountable or transparent in spite of this "engagement".

QUESTIONS ABOUT THE HCCSS CULTURE AND STRUCTURE

This raises some important questions.

Was HCCSS set up in a way intended to empower its staff and contractors while disempowering the people it serves, many of whom are already disadvantaged by age, illness, and disability?

Why does the complaints process not include service users having direct contact with managers, only allowing it through their care coordinators, thereby causing a disconnect in information sharing between clients and more senior levels of HCCSS?

To whom is HCCSS accountable? This question was posed to HCCSS without a response, although it appears from the Business Plan that the Ministry of Health plays a prominent role as does Ontario Health.

Is there service user representation from disability and elder rights advocacy organizations and service users on its Board of Directors? The information on the HCCSS website would appear to suggest that there is not. There is, however, representation by individuals who

are CEO's of financial corporations, home health care organizations, non-profit organizations, and hospitals.

This creates the impression of an overly professionalized Board with little to no input at the Board level from those most directly affected by service-related policies and practices.

Why Is HCCSS's engagement process based on a medical instead of a community-based model, causing it to be staff directed with no publicly reported entry point for advocacy organizations representing service users to provide important feedback related to systemic issues?

THE HCCSS BUSINESS PLAN – GUIDING THE WORK OF THE ORGANIZATION

The Business Plan was "framed by direction from the Ontario government" which outlines its mandate and "plays a pivotal leadership role" in its modernization (HCCSS, 2023c).

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The HCCSS website states that HCCSS reached out to "partners, staff, and the people we serve" and "engaged with more than 1600 people, including health system partners, service provider organizations, Indigenous and Francophone health leaders, our staff, and our provincial community of advisors who represent the patients, families, and caregivers we serve". As previously mentioned the "community of advisors" have very circumscribed and restricted roles in what, when, and how they can provide "input" to HCCSS.

HCCSS has not reached out to Seniors for Social Action Ontario (SSAO) with over 1200 members across the province, some of whom receive services from HCCSS, for input into its Business Plan. Consequently SSAO has had to survey its own members concerning their experiences with HCCSS in order to give them a voice in this report.

With the Ontario government directing and playing a pivotal leadership role in how HCCSS is structured, it is difficult to determine to what extent this "engagement" had an impact on the Business Plan.

Assisting Hospitals and the Government of Ontario to Institutionalize Elders

> ***"Facilitating admissions to long-term care and supporting the implementation of the More Beds Better Care Act, 2022 are just some of the ways Home and Community Care Support Services is supporting the government's plan"*** (HCCSS, 2023d).

This statement in the Business Plan demonstrates clearly the major role that HCCSS plays in the institutionalization of elders. It also shows how government control trumps the input of service users and their families. The Ontario government has emphasized the building of institutional beds rather than investing in keeping people at home. It invested $6.4 billion new dollars to build and refurbish institutions (Government of Ontario, 2022b) while investing only $1 billion new dollars in Home Care (Government of Ontario, 2022a). There is some question about whether or not even this amount was spent on keeping people at home, and the Minister of Health only recently stated in a webinar that Home Care funding would now be "expedited".

People tend to follow the money, in this case right into institutions with the assistance of HCCSS and the Ontario government's use of Bill 7, which removed elders' rights to refuse if they had the misfortune to be hospitalized and no longer required acute care. Elders, people with disabilities, and their advocacy organizations have strongly criticized the government's Bill 7, which facilitates forcing elders into long-term care institutions against their will in the absence of comprehensive in-home and community-based alternatives.

The title of the organization - Home and Community Care Support Services implies assistance to age in place, yet the organization charged with keeping elders at home also plays a significant "support" role in the government's plan to forcibly institutionalize them. According to its Business Plan, each year it places 27,270 people in long-term care institutions – about a third of the entire long-term care population of approximately 80,000 in 627 institutions in Ontario (Canadian Institute for Health Information, 2021). This is not patient, family, caregiver-centric high quality home and community care services, as the HCCSS Business Plan would suggest.

EXAMPLE 5

Client C has been assessed as requiring palliative care. HCCSS offered him the High Intensity Support at Home program which makes him eligible for up to 11+ hours of care per day. Several different agencies, numerous PSWs and medical and other professionals are involved. He has been assessed for hospice care and he has a palliative care physician. In spite of this, SSAO has been informed that HCCSS has placed him into a top spot to be institutionalized in a long-term care facility against his and his family's wishes. Placement could occur any day since he has been deemed not ready for a hospice bed. If he refuses being institutionalized, HCCSS has implied that it will remove his current home care support. His family does not want him uprooted, having to spend his last days in an institution.

HCCSS claims in its Business Plan to engage with "kindness, empathy, gratitude, and compassion" yet in this case, this dying man's and his family's wishes have been ignored

and their stress level has been increased by the treatment they are alleged to have received from HCCSS.

HCCSS's strategic priorities as outlined in their Business Plan sound great.

- **Drive excellence in care and service delivery**, *yet it appears they have no mechanism or effective information or management system in place to determine what the client experience is. Long-term care institutional placements are supposed to be collaborative, yet some SSAO members are reporting that they are anything but as the example above shows. The Business Plan states that initiatives in the plan will be "measured using performance indicators to ensure progress is being consistently monitored". It does not state how this will be monitored or what action will be taken if progress is not made. There is no public information available on these "performance indicators".*
- **Accelerate innovation and digital delivery,** *yet as attested by the CEO of HCCSS the organization is not in compliance with Ontario's Digital and Data Directive of 2021 as of a year ago, and no work was underway to address this problem due to resourcing challenges. Furthermore it was questionable whether or not information was being handled appropriately since corporate records had apparently been created "without a structured or documented approach to the management of these records within the appropriate legal entity." The CEO admits that "information may not be protected, classified, retained, and disposed of in accordance with applicable policies" in her attestation (Martineau, 2022), again due to funding and resource challenges.*
- **Advance Health System Modernization.** *HCCSS is now sharing its knowledge with Ontario Health Teams to create "a more seamless journey and maintain access to services [clients] need". One of the areas it is doing this is palliative and end of life care. As the example above shows, this "sharing of HCCSS's knowledge" may not necessarily be a positive development if this is the manner in which HCCSS handles end of life care.*
- **Invest in Our People**. *SSAO Client Survey Information and direct communications with clients of SSAO show that there is a revolving door of PSWs providing care with little information or preparation thereby necessitating family involvement in training and advocacy with HCCSS staff. This lack of supervision, communication, and information sharing does not contribute to retaining staff or serving clients. Furthermore, as stated previously, contractors providing services to HCCSS clients report being able to provide care only about 50% of the time due to staff shortages. Some staff have reported to SSAO that HCCSS is heavily staffed administratively, but there are shortages in front-line staff.*

THE LATEST WRINKLE: SYSTEM MODERNIZATION

On September 11, 2023 Ontario Health Teams invited people to attend a webinar on modernization of the home care system. Presenters were Hon. Sylvia Jones, Minister of Health, Betty Lou Kristy, the Chair of the Minister's Patient and Family Advisory Council, Dr. Catherine Zahn, Deputy Minister of Health, Cynthia Martineau, CEO of Home and Community Care Support Services, and Matthew Anderson, President and CEO of Ontario Health.

The presentations were rushed, using a slide deck, and no audience questions were entertained. The presentations, even answers to the questions provided by the moderator, Assistant Deputy Minister of Health Integration and Partnerships, Alison Blair, seemed scripted.

Slide decks, as of this writing, have not been made available to those who participated in the webinar in spite of SSAO having asked for them. Ontario Health has responded to SSAO's request for an online Zoom session for its members, but at this writing, no date has been provided.

The ongoing concern about HCCSS and some government officials being unwilling to engage with the public is interfering with the development of responsive public policies that would help improve home care services for vulnerable people.

In the webinar the Minister referred to the Ministry's report Your Health: A Plan for Connected and Convenient Care whose main points can be found at this site: **https://www.ontario.ca/page/your-health-plan-connected-and-convenient-care**

Modernization appears to introduce a new wrinkle into the already chaotic provision of in-home support, and may represent yet another iteration or evolution by yet another government of a system that needs to be stabilized and made responsive to those it is intended to serve. We have already seen the clumsy handover of CCAC's to LHIN's to HCCSS. Now we are to apparently also witness these additional changes:

- Consolidation of the 14 HCCSS offices into a Shared Service organization to facilitate centralized contracting and purchasing of medical equipment etc. Legislation to do this may be introduced in the Fall;
- Shared Services will likely include updated contracts, better reporting and rates, volume allocation, and new delivery models with an emphasis on Hospital at Home approaches;
- Integrating HCCSS care coordinators into the 50+ Ontario Health Teams (OHTs) across the province (access for service users would appear to continue to be through existing channels), which will take on local delivery of home care;

- Expediting flow of the government's promised $1 billion in funding for home care – much of which will be used to recruit more staff and pay them better to stabilize the workforce;
- Care is to be more accessible, and connected to primary care and more of a neighborhood model with an attempt to break down the barriers between HCCSS and community care agencies;
- The discharge of Alternate Level of Care patients from hospitals continues to be a priority, but Ontario Health teams are to introduce "tools" to help keep people at home longer.

There are no details available at this time concerning these initiatives.

The government believes that decentralizing services even more and introducing more changes will somehow create equitable access and standardization across Ontario.

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ANALYSIS AND CONCLUSIONS

In examining documentary evidence, survey feedback, press reports, and information provided in interviews with key informants, what emerges is a picture of HCCSS having significant challenges.

There is no question that there are staff and managers in HCCSS doing the best they can with what they have. But what they have is a dysfunctional system that is not conducive to good service delivery or to public accountability and transparency or to being able to receive important input by advocacy groups representing service users.

Flawed handover of responsibilities from CCAC's to LHIN's and to HCCSS

There were obvious problems with the handover of responsibilities from Community Care Access Centres (CCAC's) to Local Health Integration Networks (LHINs) to Home and Community Care Support Services (HCCSS). Now Ontario Health Teams are also in on the process of "modernizing" home and community care.

It has become obvious that government mismanagement has created chaos in the Home Care system with too many changes of name and shifts in responsibilities and systems not

designed to support the changes. Clients have suffered as a result as everyone braces themselves for what the next iteration of home care services is likely to be, and who will be responsible for them.

The CEO's Attestation in June, 2022 is rife with examples of HCCSS systems struggling to deal with handover problems. Here is only one example, and it is an important one:

> ***"HCCSS Central may be non-compliant with section 28 of the Financial Administration Act (FAA). The Community Care Access Centres (CCACs) HIROC Subscriber's Agreements were transferred to the Local Health Integration Networks (LHINs)pursuant to a transfer order of the Minister of Health and Long-Term Care (Minister), as it then was, under section 34.2 of the historical version of the Local Health Systems Integration Act, 2006 (LHSIA). A reciprocal, by its nature and composition, poses a compliance question under the Financial Administration Act because risks are shared amongst all the members; as noted below, there is uncertainty about the compliance of this specific HIROC arrangement. It is not certain from the Minister's order or from applicable legislation whether or not this increase in the contingent liability of the Crown placed HCCSS in non-compliance with the FAA and with each Ministry –LHIN Memorandum of Understanding. Furthermore, the HCSS has no direct knowledge as to whether or not this matter was addressed in Cabinet's approvals in respect of the legislative amendment that enabled the transfer"*** *(*Martineau, 2022).

Readers will get the picture. Chaos.

Service Principles That Disempower Service Users But Empower Contractors

The philosophical basis upon which HCCSS is built is staff-centered, not client-directed. Having all power centered in staff with varying levels of skill, knowledge, and qualifications who make decisions regarding the nature and amount of care a person will receive and when they will receive it sets up a "staff knows best" paternalistic system of care provision geared to the need of contracted service providers and HCCSS staff and management not service users. This type of service philosophy and the organizational culture it creates is bound to be rife with frustration and conflict for both service users and staff.

A Staff-Centred System Without the Resources to Provide Adequate Care

Home Care Ontario in a January, 2022 news release states that as of the end of December, after the loss of over 4000 nurses, its members only fulfilled requests for nursing services 56% of the time (Home Care Ontario, 2022). This confirms reports to SSAO and comments by respondents to the client survey about the unreliability of nursing support.

An Inadequate Management Information System and Lack of Public Accountability

HCCSS appears to have no workable data collection and production system which also suggests that an effective management information system is lacking. It is difficult to imagine how senior and middle managers are to effectively manage the day to day operations of HCCSS, much less address issues affecting the organization, without a workable management information system. This also impedes HCCSS's ability to provide information to the public in the interests of transparency and public accountability.

In June, 2022, the CEO of HCCSS swore an Attestation in accordance with section 14 of the Broader Public Sector Accountability Act, 2010 ("BPSAA") in which she stated:

> ***"The Ontario's Digital and Data Directive, 2021 requires all data created, collected and/or managed by ministries and provincial agencies to be made public as open data, unless it is exempt for privacy, confidentiality, security, legal or commercially-sensitive reasons. There are no HCCSS processes in place to implement this Directive. HCCSS organizations have not analyzed their data and have not applied the principles in the International Open Data Charter in preparation to release data as a result of resourcing challenges and other provincial priorities. There is no work underway to address this exception due to resourcing challenges and other provincial priorities. However, HCCSS ensures that they respond to data requests from the public in a timely manner."***

It is equally difficult to understand how HCCSS is to provide data to the public in a timely manner when it has not analyzed its own data because of resourcing challenges and is not meeting the requirements of the government's own Digital and Data Directive, issued two years ago.

Information Protection That Does Not Meet Standards

The CEO's Attestation also mentions storage and protection of information.

> ***"Due to long-standing hiring freezes and budget reductions, there are approximately 70 HCCSS staff cross-appointed to other HCCSS organizations to support the continuity of home care operations. In addition, each of the 14 HCCSSs has the same CEO and a cross-appointed Board of Directors. This has resulted in corporate records being created across HCCSSs without a structured or documented approach to the management of these records within the appropriate legal entity. Information may not be protected, classified, retained and disposed of in accordance with applicable policies."***

It is apparent that some of the basic systems required to operate a major government service are not in place.

Government Imposed Staff Roles in Conflict with Consumers

As elders and people with disabilities were decrying the government's passage of Bill 7 allowing hospitals to transport people 70 to 150 kilometres from their homes and support systems against their will to be institutionalized in facilities where they knew no one, and to have their health records also transferred without their consent, HCCSS was indicating its support in the implementation of this measure. In its 2023/24 Business Plan, the CEO stated:

> ***"In addition, we are supporting system efforts to build a more modernized, connected health care system that is centred on the needs of patients across the province. This focus was reflected in our work last year to support the implementation of Bill 7, More Beds, Better Care Act 2022, enabling the safe transition of people who no longer require treatment in hospitals to temporary care arrangements in long-term care homes..."*** (HCCSS, 2023d)

This demonstrates a "care philosophy" geared towards the needs of "the system" not the needs of the vulnerable people receiving HCCSS services. HCCSS assessors and care coordinators are now in the position of having to move vulnerable people, often against their will, miles away from their support systems in order to meet the provisions of Bill 7. This is a recipe for conflict, despair, and powerlessness for service users and their supporters. And it forces staff to act - not in accordance with the needs and wishes of their clients, but in accordance with the needs and wishes of the government and system that employs them.

EXAMPLE 6

Mr. B, a man with a developmental disability, who had been forced to live in a large government-operated institution early in life, was finally able to live in the community supported by a non-profit community agency, when that institution closed decades ago. That empowerment and independence ended for him when he was transported over 70 kilometres from his home community and everyone he knew into a long-term care facility in full COVID outbreak that had one of the highest death rates in the province during the first COVID wave, and a long-history of care-related problems that were also documented in the military report.

None of this was in Mr. B's best interests, yet that is how his life ended – in a long-term care institution, in COVID outbreak, after he stopped eating.

How did Mr. B end up in a situation like this? To what extent is a service user's safety and comfort assessed before they are admitted to a long term care institution with this history by an organization that claims to be "*committed to providing a respectful, accessible and*

inclusive environment for all patients, families, caregivers, employees, partners and the public" (HCCSS, 2023d).

It is difficult to imagine that the over 1600 people consulted for development of HCCSS's Business Plan would have approved of someone like Mr. B being transported to a long-term care institution in full COVID outbreak over 70 kilometres from his home and support system. But that is what happened to him - a tragic end to a difficult life.

Legal and Care Delivery Issues

Ian Cole and his mother, in 2013 took the courageous step of filing an Application with the Human Rights Tribunal of Ontario against the Ministry of Health and Long-Term Care. It alleged that the funding limit established for nursing services set out in regulation under the Home Care and Community Services Act, 1994 for a maximum of four visits per day was not enough to deal with his needs and help him avoid being institutionalized. The Ontario Human Rights Commission (OHRC) intervened in this case asserting that the regulation amounted to discrimination against Mr. Cole based on disability contrary to Section 1 of the Code, and is not a protected "special program" as stated in Section 14 of the Code. Other intervenors included the Canadian Association for Community Living, Community Living Ontario, and People First Ontario.

On October 1, 2015, the Ontario government was forced to amend the Regulation under the Act, and the cap on nursing visits was increased from four to five per day. The Ministry asked that the Tribunal dismiss the Application and the Tribunal denied the request. It found that the "cap" was discriminatory.

In June of 2016, the Ontario Human Rights Commission and the intervenors entered into a settlement with the Ministry wherein the ministry agreed to issue a Memorandum to Community Care Access Centres (CCAC's) requiring them to "consider a full range of service options based on client need and provide the necessary referrals to additional community support services or inter-professional resources in primary care practices for clients who are receiving or reaching the service maximums to help them continue to live independently in the community" (Ontario Human Rights Commission, 2016). The CCACs were required to advise the Ministry concerning those in this situation, and the Ministry was to refer these individuals to Local Health Integration Networks (LHINs) and assist where needed and possible in identifying solutions.

The reality is that those using HCCSS's services – HCCSS's being the latest iteration of CCACs and LHINs thus far – have little idea that this case was won years ago at the Ontario Human Rights Commission. Service users and their caregivers continue to go hat in hand to HCCSS staff, essentially begging for the services they need. This would seem to violate the agreement between the Ontario Human Rights Commission, the intervenors, and the Ministry of Health and the Ministry of Long Term Care.

Either HCCSS staff and managers do not believe they are bound by this decision, have not been made aware of it, are ignoring it, or finding reasons to justify it not applying to their work. Either way, the current service provision model is not needs based and does cap services to clients.

Care Related Issues

Members of Seniors for Social Action Ontario (SSAO) repeatedly tell us that they are having difficulty with HCCSS in obtaining the care and support that they need. This is juxtaposed against the constant posts by senior HCCSS managers on LinkedIn and other media sites celebrating their staff, visiting staff at the area offices, and generally engaging in self-congratulatory behavior.

Members of Seniors for Social Action Ontario (SSAO) repeatedly tell us that they are having difficulty with HCCSS in obtaining the care and support that they need.

The policy, ethical, and support principles upon which HCCSS is based are not currently serving the public interest as reports by service users, documentary evidence, and key informant information suggests. This creates a recipe for conflict, media attention, and litigation, and it needs to stop.

Ontario Health and the Ministry of Health which are responsible for HCCSSs, need to step up to the plate and start talking to advocates from Seniors for Social Action Ontario, service users, and other advocacy and service user organizations, and begin to make the changes necessary to create a truly client-directed, empowering system of care.

To do so would ease the current pressure on hospitals and long-term care institution wait lists, and keep people at home in their own neighborhoods and communities where they belong. Furthermore it would begin to ease the dread elders currently face as they get older that is causing them to choose to die rather than be institutionalized.

RECOMMENDATIONS

FUNDING, RESOURCES AND PROFESSIONAL ACCOUNTABILITY

1. **The Ontario government should pay out the remainder of its $1 billion commitment of new funding for home care this year, and add an additional $1 billion in funding over the next year specifically designated for:**

    - **Expansion of, and easing access restrictions for older adults to the Family Managed Home Care Program, thereby giving elders and their caregivers access to direct funding to acquire and manage their own services and supports from providers of their choice.**

- **Significantly expanded access to intensive in-home services in a wrap-around approach to support individuals with complex needs who are at highest risk of hospitalization and institutionalization.**

2. **Establish a publicly available formula indicating the criteria upon which service decisions are made that is in line with the Ontario Human Rights Commission decision of 2015 that essentially removed service caps. Service should not be contingent upon regional resources, but directly linked to OHIP, making the service more equitable and based on need wherever an individual lives.**

3. **Professional accountability of PSW's would also be enhanced by the Ontario Government creating a professional College that defines the PSW Scope of Practice, establishes Standards of Practice, and provides the opportunity for members of the public to file complaints against members whose practice falls below required standards.**

PHILOSOPHY AND CULTURE

4. **Senior managers should conduct an immediate review of HCCSS's service philosophy and organizational culture with the objective of moving from being a staff-centered to creating a person-directed organization where service users and their caregivers have a direct role in decision making and service provision.**

This should include:

- **An overhaul of the community engagement process, transforming it into an empowerment model, whereby advisors and advocacy organizations representing service users have direct input to senior managers three times a year in an open forum, and management action is reported back to participants in this forum.**

- **A clearly published feedback system for the public.**

- **A more clearly defined role for Client Relations including receipt of feedback from the public, and accountability to an accreditation body.**

- **Training and education for all managers, care coordinators, and team assistants in what constitutes an empowerment approach, using small group, case study, role plays and lecture formats provided by instructors recommended by clients and advocacy organizations representing service users and caregivers. This approach would build an organizational knowledge and skill base to support future mentoring and peer to peer support processes.**

This model is demonstrated in a Continuum of Person-Directed Culture chart developed by the Pioneer Network. It outlines a progression of service provision from the least to the most empowering for service users.

Pioneer Network, 2022 https://www.pioneernetwork.net/culture-change/continuum-person-directed-culture/

SYSTEM IMPROVEMENTS

5. **Establish a comprehensive management information system to provide middle and senior managers with information directly related to the quality of client care, complaints by clients, staffing issues, concerns about contractors, supervisory and training issues, and other matters to support their effective decision making, trouble shooting, and intervention where required.**

- **This should include an effective data gathering, analysis, and information system that meets provincial requirements and makes HCCSS information more accessible and available to the public to support transparency and accountability requirements.**

SERVICE CONTRACTING

6. **Shift the current reliance on service contracting from for-profit corporations to non-profit organizations like the Red Cross and Victorian Order of Nurses as well as community-based non-profits, and home care worker co-operatives.**

This would ensure that public funding goes into direct care rather than being skimmed off for profit. This should be accompanied by a system of sanctions for failure to provide care according to contract requirements, and a public reporting system on the track records of contracted care providers.

HUMAN RESOURCES

7. **Develop a human resources recruitment strategy that involves sending speakers to high school classes to promote a career in HCCSS. Speakers should be inspirational in their approach, and stress values that create meaning in the lives of young people emphasizing the importance of, and satisfaction to be found in caring for others. Also identify speakers to attend community college programs for graduating classes of PSWs, RPAs, RNs and SSWs to promote a career at HCCSS.**

8. **Provide extensive in-service education programs for new staff at all levels incorporating empowerment practices and service user input and participation to sensitize new staff to client needs and promote accountability and the principles of providing ethical and caring services to the public.**

9. **Partner with caregivers to build their knowledge, skills, and competence and institute a system of back-up crisis support on a 24/7 crisis line.**

10. **Review care coordinator job descriptions to include empowerment practice and system navigation skills as required for the position.**

GOVERNANCE

11. **Begin recruiting 2-3 caregivers and service user advocates for the HCCSS Board of Directors so that there is direct input to the Board related to the client experience in order to influence policy making at this level. Consumer representatives should come from urban and rural areas of the province.**

COMPLAINTS MANAGEMENT

12. **Create a direct role for Patient Relations and Quality Assurance staff in the Complaints Management Process with special attention paid to solutions requested by clients and their caregivers.**

13. **Clients should, at the beginning of the process of service provision, be provided with information about how and where to raise concerns or make a formal complaint.**

14. **Provide conflict resolution and mediation training and education to area office Directors and Patient Relations staff, and create a process for them to have a direct role in communication with complainants and in resolving complaints.**

15. **Establish a neutral, non-partisan third party to create an ethical, transparent complaints process based upon due process, and including a feedback mechanism to improve service quality.**

16. **Provide decisions in writing outlining the reasons for the decision, how it was made, and including information about how to appeal the decision.**

17. **Appeals should be handled in a timely manner according to the principles of due process, and decisions should be publicly available and published on the HCCSS website.**

Conclusion

In the event that HCCSS and/or Ontario Health and Ministry of Health management rejects, or chooses to ignore all of these recommendations and plans to continue to operate a staff-centered organization acting only as an arm of government, then its PR materials should better reflect this.

Forced transfers of clients into institutions and staff-determined needs assessment and rationed care are not examples of "exceptional care" as is currently being publicized.

The public deserves to be forewarned that this is a system and staff-driven organization where power is vested in government overseers and professionals rather than an organization seeking to empower and support service users.

The current attempts to present HCCSS as an organization providing exceptional care are misleading to the public based on feedback from SSAO members, survey data, documentary evidence, key informant interviews, information supplied by home care service organizations, contractors, and press reports.

It is Seniors for Social Action Ontario's hope that these recommendations will be taken for what they are – an attempt to provide consumer input to HCCSS, Ontario Health, and the Ministry of Health to lay the groundwork for future collaboration and mutual support to further the interests of those being served by HCCSS.

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APPENDIX A

Questions posed to HCCSS management by SSAO and HCCSS management's response

From: Seniors Ontario <seniorsactionontario@gmail.com>
Sent: Friday, August 18, 2023 10:16 AM
To: Martineau, Cynthia <cynthia.martineau@hccontario.ca>; Le, Tini <Tini.le@hccontario.ca>
Cc: Nelson, Trish <trish.nelson@hccontario.ca>
Subject: Questions

Good morning Cynthia, Tini, and Trish,

I hope that you are all well.

SSAO, in partnership with other researchers, is currently developing a report concerning Home and Community Care Support Services. When complete you will receive initial copies.

It is our hope that this report will benefit both service recipients and HCCSS, since it's findings will be shared with those responsible for health policy in Ontario and will direct SSAO's advocacy efforts with respect to in-home services and support.

I wanted to run some questions by you to ensure that our report accurately reflects our initial findings and your information, and hope that you will be willing to respond to them.

1. To whom is HCCSS directly accountable?
2. Your website states that assessors determine individuals' care needs. On what are these assessments based?
3. Your website also states that care coordinators could be nurses, social workers, occupational therapists, physiotherapists, or speech therapists. Not all of these disciplines receive training in case management. Is training made available in this regard to care coordinators, and if so, is it possible to receive more information about this training?
4. Care plans are said to be based on peoples' assessed needs, presumably as determined by the assessors. What are the qualifications of the assessors, and what happens if the person being assessed does not agree with the assessment?
5. Team assistants book client visits and communicate with clients and other professionals. Is there a job description for them, care coordinators, and assessors, and if so, is it possible to obtain copies of these?
6. If a service user advises a team assistant that the time they wish to book services is not what they require, what process occurs to resolve this problem?
7. HCCSS contracts with a range of companies, agencies, and organizations to provide care. Is there an available list of these contractors for each of the 14 HCCSS offices?

8. Is information publicly available concerning the nature and quality of services delivered by each contractor, similar to inspection reports of long-term care facilities? If so, how would a member of the public obtain this information?
9. Who within HCCSS monitors the quality and nature of services provided by these contractors, and does HCCSS have the ability to sanction in some way contractors that are providing substandard services and support or services that do not meet their contractual obligations? If HCCSS does not have this mandate, who does?
10. When a complaint arises, are Patient Relations/Quality Assurance involved? Is there any assistance available to individuals requiring it where there is a conflict concerning the provision of services and support?
11. The HCCSS website outlines what kinds of complaints can be made i.e. a decision concerning ineligibility, amount or decision not to provide services, and a decision to terminate services. Are HCCSS required to provide service recipients with a decision in writing stating the reasons why service was deemed ineligible, not provided, or terminated?
12. If there are other grounds for a complaint besides the above, such as care providers not showing up, being rude, abusive, or unskilled, or there is a revolving door of caregivers needing family caregivers to constantly retrain them, or care provision is not occurring when an individuals says they require it - does the HCCSS complaint process address these as well, or is there another process for this?
13. The website states that if a complaint is not resolved between a person and their care coordinator, that it is the care coordinator who should provide this information to their manager rather than the client? Is this the case and what is the rationale for the manager not accepting a direct complaint from a client?
14. If a complaint is not resolved at the manager level, it appears that a service recipient must request a formal review. Can you please provide some information about the formal review process? What is this process? Who does the review, and what are the reviewer qualifications?
15. The Health Services Appeal and Review Board appears to only consider complaints related to ineligibility for services, the type and amount of services received, or those that are discontinued. Does its scope involve hearing the other types of complaints outlined in #12?
16. You are likely aware that there was a decision by the Ontario Human Rights Commission in 2015 in Cole v Ontario Ministry of Health and Long Term Care. Do you consider this decision to also apply to services and support provided by HCCSS, and if so, are your managers and care coordinators trained with respect to it?
17. HCCSS seniors managers regularly post their visits to area offices and celebrate HCCSS staff achievements on social media. Do senior HCCSS managers also make visits to clients whose files are chosen randomly during the visits to area offices to determine what the client experience of HCCSS services are? If so, how frequently would these kinds of home visits to clients by senior managers occur?
18. Is information solicited from front-line staff concerning their experience of providing services on behalf of HCCSS?
19. Finally, is there a process, besides the currently restrictive engagement approach, that would allow provincial advocates to work with HCCSS leaders in addressing what appear to be systemic concerns commonly raised by service recipients and front line staff?

20. Is any consideration being given to expanding accessibility to the Family Managed Care Program whose eligibility requirements currently appear to be restrictive and discriminatory towards older adults whose families may wish to access this direct funding program?

I know this requests a lot of information, but this will be a comprehensive report, and I wanted you and your staff to have the opportunity to provide input in the report. It will also be important for all concerned to better understand HCCSS's processes with respect to care provision, and it will hopefully form the framework by which SSAO can address any concerns with those responsible for health policy.

Thank you for considering responding to this. It would be helpful if we could receive a response by September 6, 2023.

All the best,
Dr. Patricia Spindel, Chair, Seniors for Social Action Ontario

RESPONSE:

From Cynthia Martineau, CEO of HCCSS

Copied to:

Tini Le, Vice President, Home and Community Care at Home and Community Care Support Services Central and Toronto Central

Trish Nelson, Vice President Communications and Engagement

August 25, 2023 3:22 PM

Good Afternoon Dr. Spindel.

Thank you for your email requesting the input of Home and Community Care Support Services into the report being developed by Seniors for Social Action Ontario.

While I appreciate you reaching out, after full consideration we are respectively declining participation in the report.

Kind regards,

Cynthia Martineau	**Cynthia Martineau**
(she/her)	(elle/lui)
Chief Executive Officer	**Directrice générale**
Home and Community Care Support Services	Services de soutien à domicile et en milieu communautaire