



Seniors for Social Action (Ontario)



RESULTS

HOME AND COMMUNITY CARE SUPPORT SERVICES (HCCSS) CLIENT SURVEY

**ELEVATING THE VOICES OF HCCSS SERVICE
RECIPIENTS AND THEIR FAMILIES ACROSS
ONTARIO**

SEPTEMBER, 2023

SENIORS FOR SOCIAL ACTION ONTARIO HCCSS CLIENT SURVEY RESULTS

Introduction

Seniors for Social Action Ontario (SSAO) initiated a survey of members who were receiving assistance from Home and Community Care Support Services (HCCSS) in August, 2023, after learning from several members that access to in-home support was so poor that they were considering medical assistance in dying (MAID).

The results of this survey represent the experiences reported by SSAO members and families who are currently, or who have recently received services from HCCSS.

These survey results have assisted SSAO in answering specific questions as identified through documentary and other research, concerning the impact of HCCSS policies and practices on service users and their families.

This represents the first survey of service users independent of HCCSS and the Home Care industry in Ontario. It is the first analysis of the quality and impact of HCCSS service provision on service users by a provincial advocacy organization representing elders.

76 Seniors for Social Action Ontario members responded to this survey.

THE RESULTS:

Question 1: I am satisfied with the services HCCSS provides received the following responses:

35% were satisfied or very satisfied with HCCSS services.

20% were neither satisfied nor dissatisfied.

45% were dissatisfied or very dissatisfied.

Comments:

- We need more social workers to help patients/caregivers learn about what services are available and how to access them.
- Too few workers forcing inconsistencies in support and service.
- My husband needed home care after surgery and I had to take him to their office, downtown in a bad area late at night. We are in our 80's and this was not easy for us.

- Satisfied, but I need more help now, and would like some time each day of the week, perhaps two hours each day for help and company.
- Spent 20+ years using home care services. The last 8 or so were so inconsistent when the opportunity presented itself I switched to Family Managed Home Care. I was already hiring private care givers so...so other than paperwork (for some "roll your eyes at requirements") it was not much more work.
- Never the same person always late.
- All communication is treated as time sensitive. The care we receive is outstanding!
- 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.
- Costs of home care services, PSW.
- One hour a day is not enough. No care regarding hearing issues. Many people can't use the phone and are not given any other way to communicate with family so off they go to a care home. Hearing devices like google Home, and hearing aid maintenance should be part of the services. Are they awakened by a fire alarm while sleeping? Can they hear a doorbell? Pretty essential!
- No flexibility allowed.
- The coordination and communication can be improved to reduce the stress of clients .
- What are their services?
- She comes on the correct day, and helps with bath.
- In my experience they do their best despite funding constraints.
- Lack of funding for CSS Reliant on caregiver support Inadequate relief for caregiver CSS should be 24/7 not 8-4
- They are a good help but could do more (ie basic exercises with my mom; some claim they're not "qualified" but that's just ridiculous).
- My husband, who died on January 5th, was on palliative care at home with pulmonary fibrosis.
- Providers have been good, some are excellent. But providers change ... therefore, one needs often to train or orient the workers to personal needs/ process.
- Management is not participatory - very one sided. Client should have a say on the services provided.
- More different types of services are needed- not just a focus on PSW care, more hours for personal care are needed. More clear understanding or processes, More follow up after discharge- some people may have short term help and then forgotten about HCCSS CCs do not seem confident in how to support people with addictions/mental health and are reluctant to even enter homes at times. I have heard from CCs that management prevents them from "thinking outside box" and although they want to help, they are restricted.

- I felt that HCCSS only presented solutions for problems at hand- not necessarily in preparation for what's to come.
- 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.
- People are treated like cows and left for hours in their own excrement....walking people are no longer walking after being there a month.
- Consistency of care and accommodating clients needs is poor.

Question 2: I found it easy to access HCCSS services received the following responses:

55% felt care was easy to access.

47.5% said it was not easy to access.

Comments:

- Depending on agency, inconsistent directions.
- It was set up by the hospital.
- While I have been working with them for a few years, it took a lot of digging to find a fair wages organization that emphasizes the importance of the quality of life for the caregiver and the client.
- We searched for awhile to see what was available to us and then focused on HCCSS.
- I had access via the Memory Clinic.
- The issue is not with the contact, it is with the services contracted by Home Care.
- Setting up service was OK but maintaining and understanding optional services is difficult and confusing to arrange. She lost physiotherapy care cuz she canceled appointments. She has some dementia and can't remember appointments and can't remember that she will lose services if she cancels. No one has helped her with memory care strategies which she needs.
- It was from hospital . It's important that the hospital continue to coordinate with HCCSS. I have the feeling they want to just toss it across the fence rather than help with an easy transition so the client doesn't end back in ER in a few days or weeks. Also we were discharged and should have had care the next day but waiting almost a week before psw came. Waited over months and still waiting for nurse practitioner.
- Waiting lists Unable to access directly must be through 3rd party.

- Terribly understaffed which meant lengthy wait times and irregular appointments for things like physio, occupational therapy, counselling, and poor communication. His counsellor just disappeared with no follow-up. I had had to agitate to access any of these services.
- Is sometimes hard to get in contact with staff to make a change or to find out what is happening.
- Easy to call in and provide information for intake After that- for assessment, it is difficult.
- In general, with persistence, HCCSS tried to be available.
- Have used HCCSS 3X now and each time there was only a short wait.
- Interminable voice message before able to leave message, reported to HCCSS , nothing changed.
- Was able to get accepted into the program, but after that, the response was inadequate.
- It took over a year to navigate the system and provide justification needed to qualify.
- Hospital forced mother in.

Question 3: I found the care provided to be Very High Quality, High Quality, Neither High nor Low Quality, Low Quality, Very Low Quality received the following responses:

23.8% felt the care was very or high quality.

56.4% felt the care was neither high nor low quality.

20.52% felt the care was low or very low quality.

Comments:

- It depended on the actual clinician whether the care was high or low quality. Lack of continuity of care (revolving door of care providers) definitely negatively affected the care received.
- Mostly good PSWs but underpaid and inconsistent scheduling.
- My husband needed his catheter cleaned and changed and they told him to do it himself. Our daughter-in-law had to do it for him but what would have happened if we didn't have a nurse in the family?
- Efficient, friendly, kind and caring.
- Inconsistent. Lots of chatter about matching the needs of the client to the abilities of the caregiver but you really had to push for that.
- We have a wonderful care worker.
- I would say 'adequate.'
- As an example one psw left my quadraplegic husband on the toilet because she had another client appointment. He was on the toilet

for 2 hours with only myself to guard him, and he was in tears as was I until my private PSW arrived to help. Unbelievable. Often I would receive a call from the PSW agency saying no one was coming - entire month last summer was like that.

- Not able to be there when they come. My mother says they do little to help her.
- Workers want to leave as soon as possible.
- Lots of different people showing up whenever without a regular routine.
- We have hired a private PSW, and the care from her is superior.
- Depended on quality of staffing available affected by training & low wages - many staff still work 2-3 jobs.
- They are kind and helpful, but could do more. One stays, on average, 35-40 mins when it's supposed to be an hour...
- Getting consistent, quality PSW care was a nightmare. We were unable to have the same PSW for his bathing. We were unable to establish a predictable schedule; the visits were totally random. There was no respect for his needs or dignity. In the end, I decided it was worth it to go with a private company to have the same PSW that he could know and relate to come on a regular schedule. He loved Jessica and made his last days so much better.
- Average.
- Care was inconsistent. Some were great. Others not do much.
- In all cases the care was given by OT and Speech therapy.
- Inconsistent- contracted agency showed no consistency with tasks their staff could do/ not do certain.
- Caregivers do not appear to be highly trained.
- Horrible.

Question 4: Care was provided to me or my loved one at the times I needed it received the following responses:

53.85% said care was provided when they needed it.

48.72% said care was not provided when they needed it.

Comments:

- 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.
- Can't get steady workers.
- Yes but not well.
- But not long enough now.
- Because I insisted. Therefore we were "uncovered" many many times and I was noted to "refusing service" which could have gotten us thrown off the service completely.

- Always waiting for another assessment.
- As the spouse who is not able to give the care needed I was very appreciative of the access to this service.
- Hit and miss. Nurses were always there.
- Only one hour a day..not enough. We supplement with private care. Very expensive.
- Not always.
- Hard to ask seniors to wait in bed for hours before someone comes to help them with their morning routine at noon.
- Upon discharge from hospital but two hours a week is not enough.
- Not enough, and silly rules like they can't make her a sandwich unless they also hand her a shirt.
- Care is based on staff availability.
- Not without a struggle.
- I found pre-pandemic, the CCs and PSWs I had encountered very helpful, it has changed.
- 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.
- For the most part.
- 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.
- Not by the organization charged with providing this care during a critical time.
- Workers insisted on coming on their schedule, not the client's booked times. Refused to come if they had to travel more than a few kilometres. Seldom received visits on weekends, and almost never on holidays.
- The agency created the schedule and our family had to conform to it.
- Except the day the worker showed up drunk.

Question 5: Care workers were reliable and came when they said they would received the following responses:

56.76% of respondents felt that care workers were reliable and came when they said they would.

48.72% felt they were not reliable and did not come when they said they would.

Comments:

- Some no shows.
- They didn't come at all, we had to go to them.
- Mostly.

- As long as you had a care worker who liked her job and was willing to work.
- Very dependable and hardworking.
- However, one worker never fails to let me know he has to leave 15 mins. before the hour is out in order to get to his next client. I never get a full hour from him.
- It varies but client doesn't have a good sense of assurance that people will show up.at all. I made arrangements for banking and no one showed up for my respite relief.
- Usually, but would phone occasionally to change the time but always came on the right day.
- Care workers not in control of scheduling (2) care is delivered at convenience of agency not the client.
- Yes, for the most part.
- There were a few exceptions where care worker did not notify about the time she was coming.
- Majority of my experience is monitoring whether our clients had their PSWs, I know HCCSS uses other agenices to complete this task. I have had many clients share they have not had service, no follow up, no reschedule, no answer as to why.
- Generally the care workers came when they were supposed to, but sometimes they were a no-show, often they weren't given background/patient history as to why they were even there.
- For the most part.
- Arrived but often left well before the hour was over- some did extra helpful tasks, others did nothing but tend to my spouse then left without doing other small task for him.
- There seemed to be a lack of coverage for sick days or other events like vehicle breakdown.
- If ur Immobilie God help u...they will never come.
- Mostly after the drunk worker we moved to private paid help.

Question 6: The quality of care provided was Very Positive, Positive, Negative, Very Negative received the following responses:

73% found the care provided to be positive or very positive.

26.31% found the care provided to be negative or very negative.

Comments:

- There needs to be a positive/negative selection, because that has been our experience. Sometimes it was good and other times it was bad.
- They were polite and explained the procedure but didn't show us how to clean the catheter.

- Occasionally the care worker "cut corners" to get to the next job or get the day over with.
- Generally, yes but everyone is different. All have been pleasant.
- My mother says the people who come vary and don't know what they are supposed to do sometimes.
- Workers interested in finishing job and leaving early.
- I believe staff are trying given the shortages. I think caregivers should have a driving force in determining their care and controlling the assignment of it. Care is very personal and to use a middleman is difficult if the communication isn't sufficient. You feel like an object and a task vs a person living out your final days with quality & love.
- In many cases however found in some cases care workers would leave early.
- D's visiting nurse was the same throughout, and she was conscientious, gave him quality care, and took the time to build a relationship with him. She was excellent. All the other professionals seemed to be just « passing through », no commitment, and rushed/overbooked.
- Average care.
- BUT again inconsistent. No two workers from same company performed the same tasks at the same level of competence.
- Poor attitude to the work and to the client's expressed preferences. Poor attitude towards their employer and often expressed it vocally. Insisted on doing things for client that were not needed, nor in her care plan. Just seemed to assume all clients required the same care. Some workers were pleasant while others were abrupt and impatient.
- Caregivers were pleasant but evidently under-resourced and not well supported by their employer.
- Some workers were kind but for many it was just a meat shop.
- Limited.

Question 7: The HCCSS complaints process worked to resolve my concerns received the following responses:

25.8% of respondents felt the complaints process worked and resolved their concerns.

74.19% felt the complaints process did not work and did not resolve their concerns.

Comments:

- Our case worker was a sympathetic listener, but her "hands were tied" so most of the time did not resolve my concerns.
- Couldn't get enough workers.
- I clicked yes, but I haven't had a complaint.

- They tried but they were limited in what they could do because of the contracts with the agencies they were tied to.
- No complaints. All work to make the service helpful and appreciable. I cannot do what they do without consequences to myself.
- Haven't tried..didn't know about it
- Not really sure, but you don't have other options. Shouldn't taking continuous complaining to get needs meet. Calls are returned in 3 business days which I find long.
- No complaints were put forward.
- Fear of retaliation by both HCCSS in event of registering a complaint.
- The Care Coordinator was very responsive and involved. She visited our home twice to get a sense of D's needs and I know that she was frustrated that she couldn't access better services for him, particularly regarding the PSW situation.
- Response is neither yes or no. mostly positive ... sometimes hard to get in contact with the case manager.
- Not sure if this question means that we have filed a formal complaint- I answered "no" in the sense that my complaints really didn't seem to be heard or acted upon.
- Seldom or never heard back Lack of personnel , poor pay, and poor supervisory attitudes within system made it fail in many ways.
- HCCSS simply switched care agencies, but no change in supports.
- I filed a complaint never heard back.

Question 8: I would recommend HCCSS services to others received the following responses:

60.53% said they would recommend HCCSS services to others.

39.47% said they would not recommend HCCSS services to others.

Comments:

- Only because there isn't an affordable alternative. Also there were times when the HCCSS services worked well and my care recipients received the care they needed.
- Community support can help keep people live in place and keep people out of Institutions.
- But still would like more time with help and companionship.
- Already have many times.
- If you don't ask for what you need and want the services will never improve or expand. Why the name change again?!? It has never changed the service in my experience.
- Absolutely!
- What choice do we have? I was desperate.

- Only because there is little else affordable available.
- It's frustrating process and highly stressful.
- For the basic care.
- As there is little choice I would have to say yes.
- It's important we have this service and we rely on it.
- In Ontario there's no other option unless you can afford to pay out of pocket.
- People need to have the help they need, so that they are not in danger ... and they do not overload their family care givers.
- As a need.
- For those who don't have money for private care/ services- It is all we have!
- Too frustrating and upsetting to client and family. Problem is that some minimal care is sometimes better than no care at all.
- Institutionalized grandma and grampa.
- You need the help.

Question 9: Comments on what is Best and Worst about HCCSS services.

Best:

- Community Home Care keeps people in their own homes and not in institutions.
- On time, efficient, friendly, reliable but not enough time here, need help every day.
- When they met with the caregiver, they made her feel welcome and supported. She'd come from a very toxic work place and is now so much happier.
- I'm so very happy that we chose HCCSS.
- What is best is * There is a service available. That is very re-assuring * Persons are generally pleasant and cooperative * Basic needs for the visit are met.
- Some staff are pure gold- we need to keep them in the system and find ways to reward and acknowledge them.
- Consistent caregivers were wonderful. Overall we were very lucky getting 4 hours per day.
- Level of care and compassion on part of PSWs under COVID difficulties
- Getting the same PSW each visit.

Worst:

- All Community Care Agencies should be NOT FOR PROFIT. Remuneration for workers ie: poor salaries, rural mileage needs to be paid appropriately to provide incentives to entice employees.

Too much worker change, necessitating continual retraining of workers to individuals' idiosyncrasies.

- What is worse is * If they leave before the hour thus spending just 45 mins not 60 mins. * Not getting the same PSW each visit.
- The processes and communication need to be improved greatly - people should {not}feel like they are bounced back and forth. 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.
- 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.
- Some needed more training. Still had to pay out of pocket for additional 4 we required. Luckily we could afford it.
- Attitude and treatment of PSWs by their agency supervisory staff , attitude and lack of moral support of PSWs by both agency and HCCSS, lack of adequate hours, poor communication system and seeming lack of compassion and support to fight for patient rights.

GENERAL COMMENTS:

- We need more services and to treat our home care workers better, with better pay. As older adults we don't just need nursing care, but home care i.e. food prep/taking us to appointments-my husband has cancer, grocery shopping etc.
- 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.
- Good hygiene, courteous, punctual I find that the lay public gets confused by what this service provides.
- My husband died in January 2023 from aspiration pneumonia, which went undiagnosed by the nurses for TWO months even after repeated questions by me about symptoms. After hospital diagnosed him, one of the nurses said she suspected that but didn't want to worry ME!! They were caring people and one in particular was excellent, but I feel they were not equipped to make sound judgement calls on severely ill people. They were always communicating when they would come, but often my paralyzed husband had to wait hours daily in bed waiting for his dressings to be changed. Bottom line, inconsistency, mixed skill level.
- I do not hear from them unless I call..sometimes they call me and other times another of my siblings. A simple email to all interested parties would be much better. (call about reassessment..not to tell

us how she is doing). No interim reports. She needs far more than 1 hour a day.

- The care worker provided what she was supposed to do...but was not as diligent and as positive as the private PSW.
- There are some fine professionals struggling within a system that does not support them
- HCCSS seems to be about solving the problem at hand only. HCCSS does not look at the big picture, nor do they seem to provide resources above and beyond what is being asked of them in the moment. HCCSS felt a little secretive- only giving info or direction when needs are urgent- otherwise they are not discussed. Also, HCCSS seems to work on their own schedule. Crisis matters take too long to address- not timely. It is difficult for caregivers who also work and have their own families/responsibilities to adhere to 9am-5pm type access.
- Once a volunteer is assigned, it seems they are on their own to provide support with zero oversight or support.
- The system as currently structured needs a complete re-design. It doesn't work for many people, and that appears to be primarily an internal failure at comprehensively understanding what clients and their families really need, and that they need the supports to be prompt, appropriate, reliable and respectful.
- Having proper care in our home would be immensely more helpful than the current situation, where our family member must live in an assisted living facility because of lack of access to adequate home care.

ANALYSIS:

These survey results paint a picture of a home and community care support service system that is struggling to provide even adequate care to service recipients in the absence of appropriate levels of funding and resources from the Ontario government.

Many complained of not receiving enough help tied to their actual needs.

There were both kudos and complaints about those providing the direct care with some respondents having had very good experiences with very conscientious staff, and others indicating concern about workers regularly leaving early or just wanting to get the care "over with". Many described the care as average or adequate.

The complaints process is clearly not working. Many respondents are not aware of a complaints process, and some indicated that follow-up was poor or non-existent. This raises the question of to what extent middle and senior managers and the patient relations and quality assurance teams in HCCSS are

even aware of complaints or patient experiences that need to be addressed.

Respondents said they would recommend HCCSS to others, but in many cases only because nothing else was available.

There appear to be some issues with agency contractors.

As one respondent said, the current system needs a re-design because it does not work for many people.

These survey results will be included in a more comprehensive report by Seniors for Social Action Ontario concerning Home and Community Care Support Services currently being prepared.