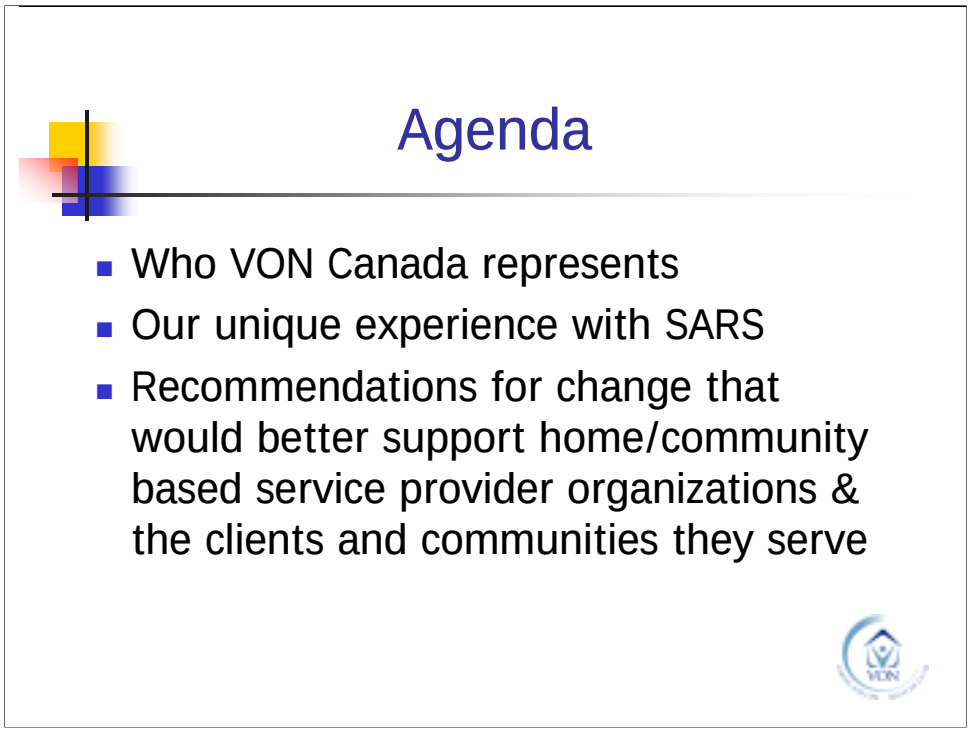
VON Canada's Brief to Independent SARS Commission

Janis Leiterman, RN, BScN, MPA
National Director Clinical Services
VON Canada

VON Canada submitted its SARS brief to the Canadian Nurses Association and the Community Health Nurses Issues Group, which were rolling up numerous briefs on behalf of nurses.

VON Canada wanted to present independently because:

- we need to ensure that the Home & Community Care voice is heard distinctly
- and because we represent more than nurse service providers.



To understand the context of this presentation you will need to know about VON and who we serve.

I will then outline VON's unique experience with SARS. In many places, I'm simply going to tell stories that I think best illustrate our experience within the health care system.

Finally, I will make 10 recommendations for change that would better support home/community based service provider organizations & the clients and communities they serve

VON recommendations flow from the unique experience of one home and community-based service provider organization with SARS.

VON Canada is a national health organization and registered charity offering a wide range of community health care services that meet the needs of Canadians from coast to coast. VON is dedicated to:

• being a leader in the delivery of innovative comprehensive health and social services

• influencing the development of health and social policy in Canada

• quality improvement (CCHSA accreditation)

Our core values are caring for life through respect, participation, responsiveness and courage.

VON has a range of service providers including RNs, RPNs, Personal Support Workers, and volunteers; a diverse patient population, and, as a result, a broad range of services.

We have more than 7000 staff and over 13000 volunteers, more than 50 different programs and services (which vary branch to branch). We deliver these programs and services to more than 1,300 communities across Canada, the bulk of which are in Ontario e.g.

• VON has 64 branches in Canada, 29 in Ontario.

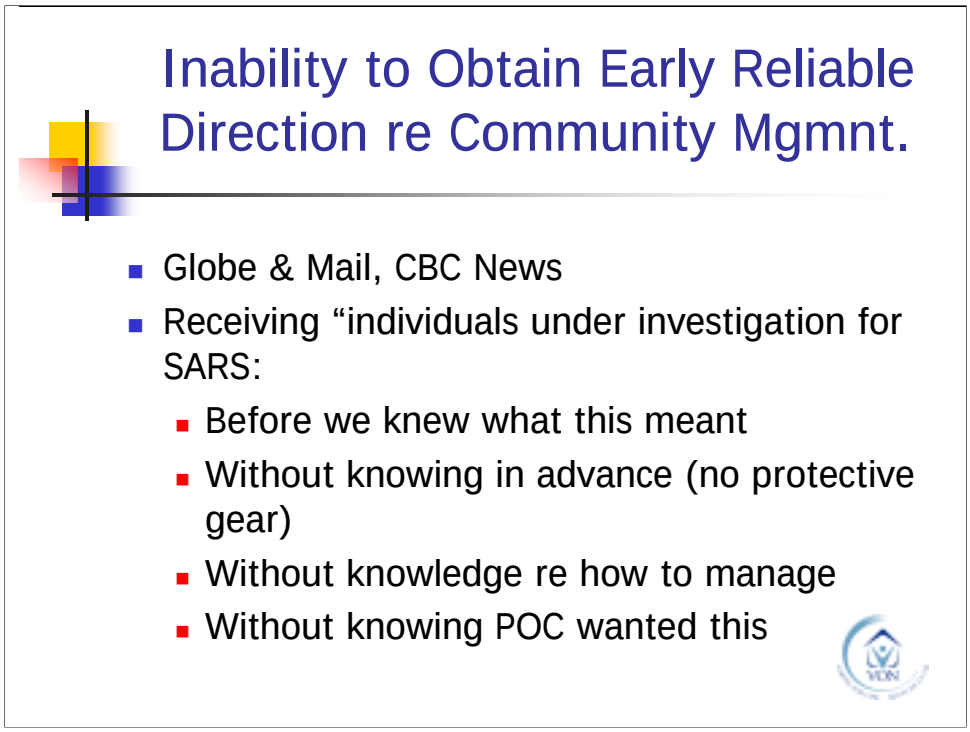
• more than 9300 volunteers active in Ontario

In Ontario, VON home care services are primarily contracted to CCACs through the RFP process. Service delivery includes expertise in the areas of palliative care, wound care, diabetes and foot care requiring skills sets such as IV therapy, pump-controlled analgesia, home dialysis and ventilator care. Community Support Programs include MOW, Adult Day Programs for Alzheimer's patients, Volunteer Transportation, Client Intervention and Assistance, Mental Health Volunteer Visiting, Hospice Visiting, Parent Infant Support.

Services delivery sites include homes, clinics, and community centres. Service is delivered via visits or shifts.

SARS challenged both the personal and professional resources of VON staff and volunteers. Debriefing revealed a shared concern about how we would have continued to practice safely if this crisis had gone on for any longer. Surge capacity was limited and there is an acute awareness that in an Influenza Pandemic, a good percentage of us will be too ill to work or dead.

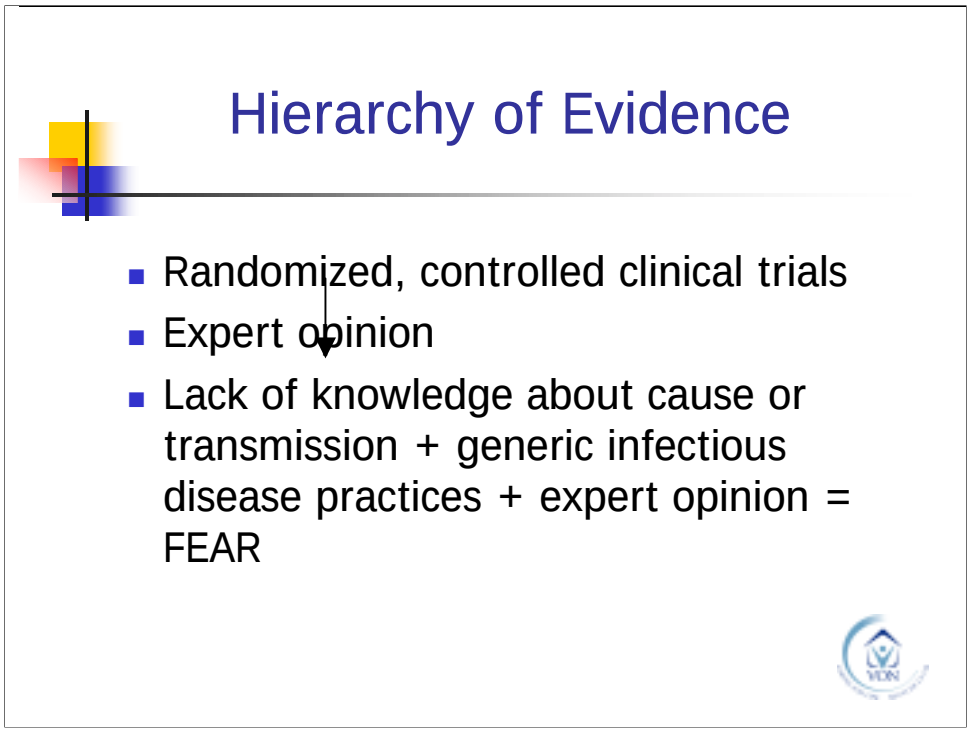
In general, we felt good about having risen to the occasion. VON had the infrastructure to communicate effectively and we had built relationships internally and externally to allow us to pull together as a team. There's no denying that it was harrowing at times, but we came away knowing that we had a lot to contribute to the safe care of Ontario citizens at the planning, policy and delivery levels.



In the beginning, my best source of information was CBC and the Globe & Mail.

VON Canada branches in Ontario were receiving Persons Under Investigation for SARS (PUI) before we knew what this meant (i.e. staff thought they were SARS patients); without knowing in advance, etc. One example is a nurse who had just completed his own course of chemotherapy, visiting a PUI for SARS without any info from the CCAC re the patient's status – so there was no indication of the need to wear protective gear. The next day, when VON was informed by the CCAC of the patient's status, the nurse had already seen a full day's caseload of other patients.

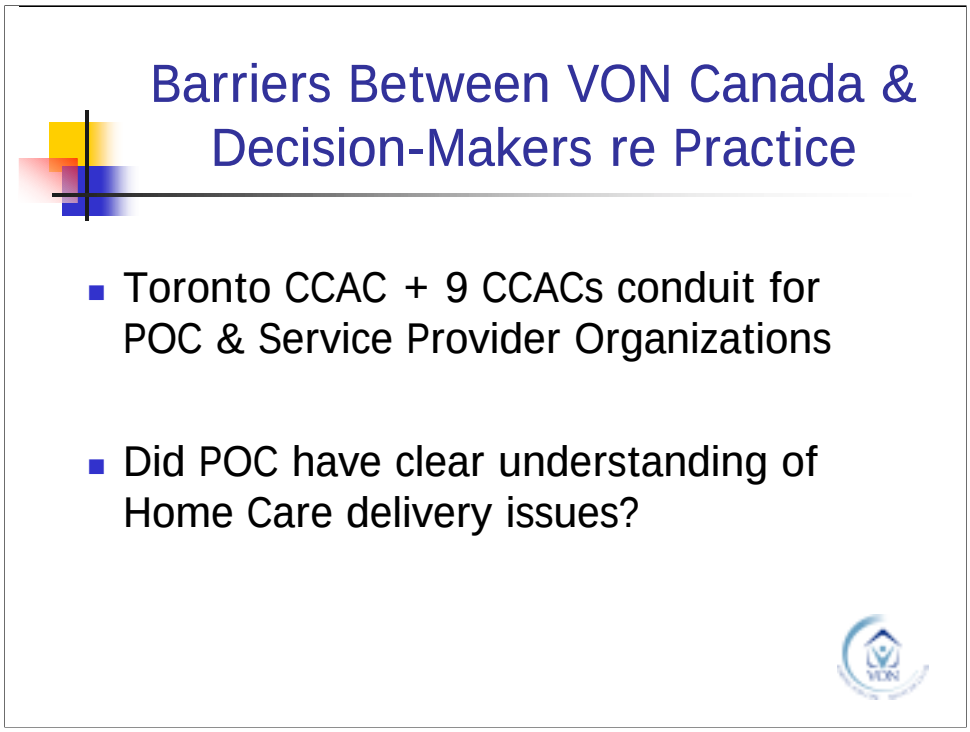
This lack of info for the Home Care/Community sector lead to exhaustive efforts to get info from the Ontario government for the community. I had heard via the media of Minister Clement's 2 or 3 point plan, but by the time we were receiving PUI for SARS, there had still been no reference to the community sector. VON's message to govt. was that VON wanted to play any role possible in supporting the citizens of Ontario, but only as part of a planned and purposeful strategy. We did not want to find out after the fact that VON had put anyone at risk by transmitting disease from home to home. I eventually contacted the Minister's office and after that was told that my questions would be moved from Dr. Young's office to the Science Committee of the POC.



Evidence-based practice is the best way to ensure effective efficient quality care. There is a hierarchy of quality of evidence which is related to strength of practice recommendations.

Evidence from one properly randomized controlled trial is ranked 1st or highest. Evidence from at least one well-designed clinical trial without randomization, preferably from more than one center, from multiple time series or from dramatic results in uncontrolled trial is ranked 2nd. Expert opinion is ranked 3rd. . It is the lowest level of evidence. Expert opinion is extremely valuable however, in understanding and applying the findings of higher levels of evidence and ***particularly*** in the absence of any higher forms of evidence.

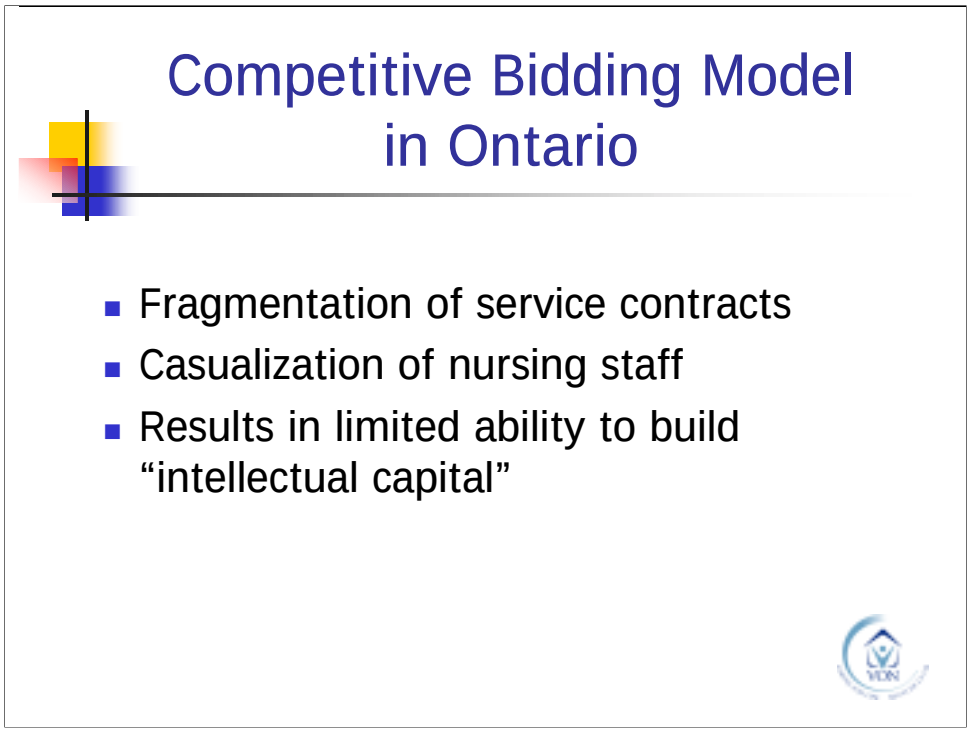
The first MOHLTC Dr. that responded to questions re transmission risk and protective gear required in the community said she could "*state with confidence that there was no need to mask*". I'd had a past working relationship with her and was not confident about her critical thinking. The next Dr. reiterated this position, but sounded tentative. Interviewing revealed that she had been on the job one day. I proceeded to base VON policy on Health Canada infection control documents and my own critical thinking. ***This story*** is intended to illustrate that when you are relying on expert opinion, you need to trust the expert, whether from past experience, from how their message is framed, from understanding how the process works, or from participating in the process. *When something finally came out in writing the direction to wear full protective gear for PUI for SARS was very clear.* ***I don't have*** inside information on what contributed to this inconsistency. I'm sure the rate at which knowledge was evolving had a great deal to do with it. But I also wonder if it reflects a lack of sufficiently prepared infectious disease specialists with a good understanding of the home care sector. This scenario played itself out at the national, provincial and regional levels. For example, feedback from nurse managers revealed that calling their regional PHD sometimes resulted in speaking to a casual PT worker giving advice about which they knew very little – likely reflecting under funding of the PH sector and recruitment of emergency staff. This advice, at times, varied from worker to worker, between levels of staff, and from region to region. I want to emphasize that there was excellent support from PH and CCACs, but responses often varied. I have 4 quotes to share from VON's internal debriefing that illustrate a range of experiences. "Our branch doesn't have any CCAC contracts so we contacted PH for our advice. They were always excellent in terms of their response times." "The PHD was of little use because I couldn't get through on their lines." "The PHD was difficult to access. My voicemail messages were never returned." "Our CCAC advised us to call the PHD, but then they didn't always like the answer and didn't want to comply."



The Toronto CCAC banded together with 9 other CCACs to act as the go-between for the POC and the providers. They did an excellent job, but it was clear from early POC directives that policy-makers did not have an understanding of home care delivery issues.

It was frustrating receiving the information from service contractors (CCAC), asking questions, having questions relayed to the POC through (non-clinical?) contractor staff, and then waiting for responses through them, which inevitably led to more need for clarification.

The inability to have a direct & dynamic discussion between home/community care providers and infectious disease experts/policy makers slowed the access to relevant information in an emergency which was frightening for staff, volunteers, and clients, given the rapidly evolving knowledge base and degree of risk.



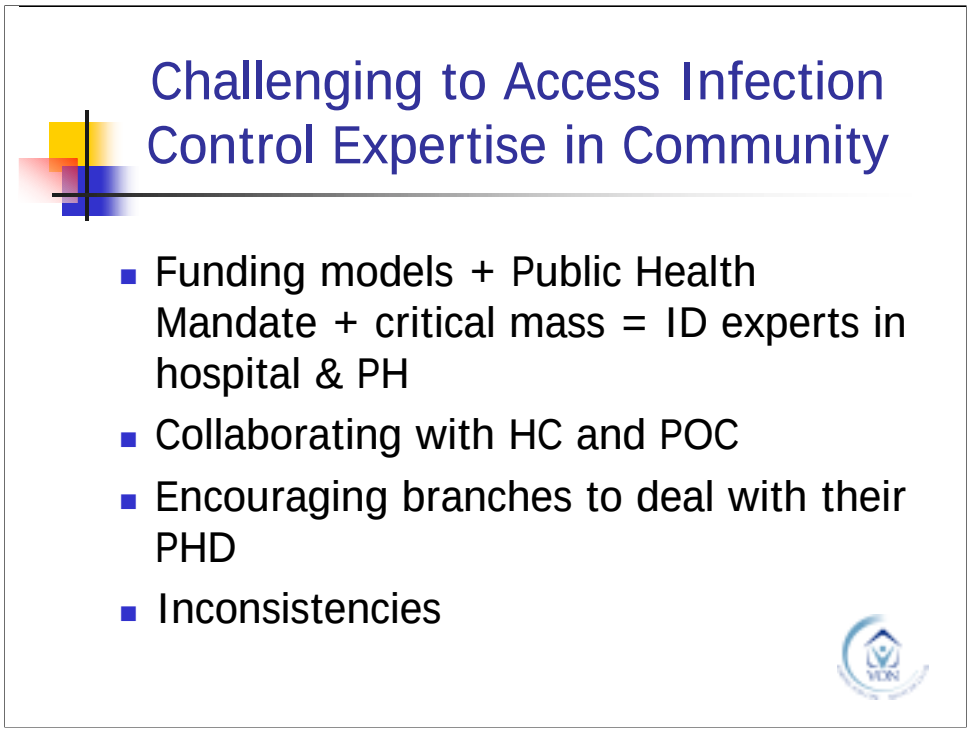
Competitive bidding or managed competition model in Ontario has created:

• Barriers to sharing information/resources with all home and community care service providers because it could be the competitive edge in any RFP process.

• fragmentation of service contracts (e.g. multiple providers of varying size and resource capacity to support quality evidence-based practice);

• casualization of nursing staff (which results in nurses holding 2 to 3 jobs, often in different sectors, limited opportunity for new nurses to truly consolidate practice and build experiential knowledge, and increased movement from employer to employer)

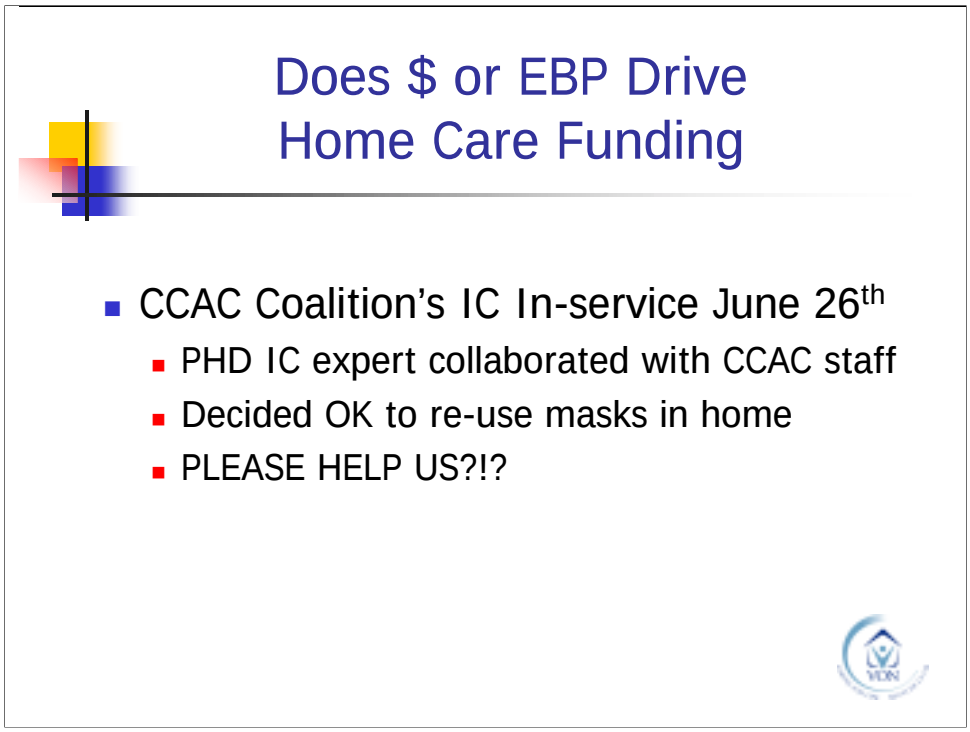
The last two factors result in limited ability to build "intellectual capital" – there isn't enough stable critical mass in specialty areas to build expertise. Home and community care is in and of itself a specialty. It was easy to see both the risk and the hardship that these factors created during the SARS experience.



Infection Control Practitioners/Experts tend to be hospital based because of global funding models and a "critical mass of ***visible***" patients, and in PH because of their mandate. That's what makes the Home & Community Care Sector so vulnerable. We are invisible.

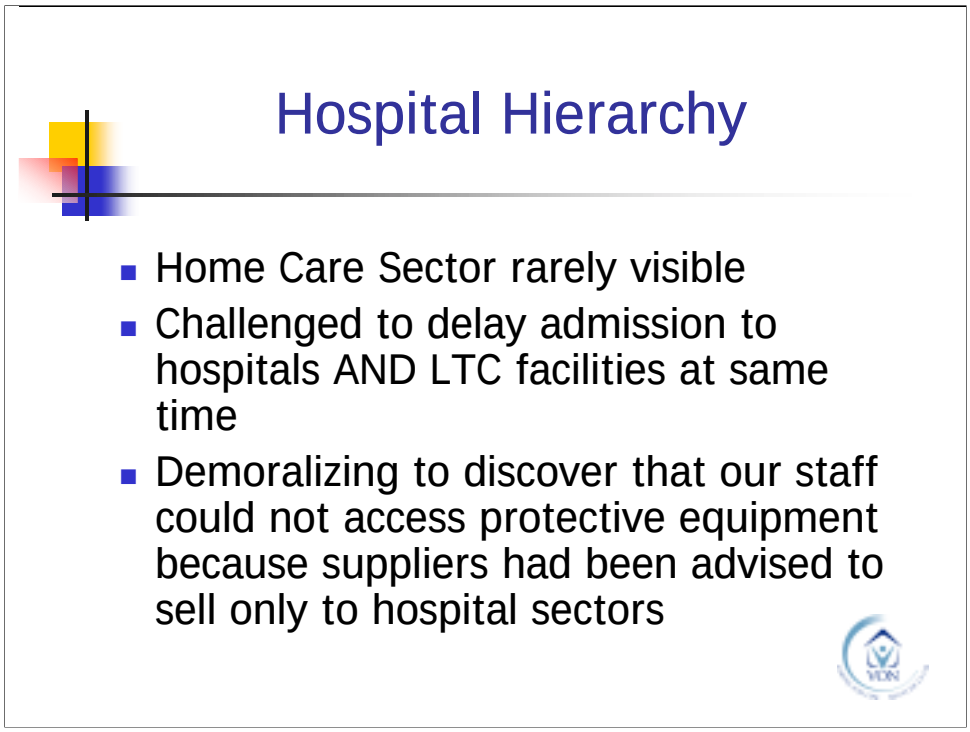
At the national level of VON, I was reviewing/collaborating with both Health Canada and the Ontario practice guidelines trying to identify the most evidence-based position where there were inconsistencies. Branches were encouraged to deal with their local PHDs because they are ultimately responsible for ID management in their region. IC practices might vary based on epidemiological profiles in different regions. It was challenging for all to deal with inconsistencies amongst the 3 layers of government.

Even staff manning the SARS Hotline for professionals is challenged to accurately interpret the directives that are coming from the committee of experts. THEY WERE EXCELLENT and I was very grateful for their 24/7 presence and commitment to support. They asked many questions to try and understand the home care context of the question, but I wondered how how many layers my question might pass through before reaching an expert. When you are basing policy on the lowest level of evidence (i.e. expert opinion), it adds confidence and credibility to know whom the expert is. The only certain confirmation of a position was if the answer to your question appeared in the next communique or got rolled into the next version of the New Normal Directives.



Does money or evidence-based practice drive CCAC funding of home care practice? I attended the Toronto CCAC Coalition's Infection Control In-service June 26th, which was offered to all CCAC provider organizations. They had invited an Infection Control expert from a PHD to speak. She gave an excellent and informative presentation, but there was no one there from the POC SARS Scientific Committee and on asking if we could walk through the New Normal Directives together they were no clearer on *outstanding* issues than I was.

This reflects my understanding that the role of the CCAC does not include housing clinical expertise or giving direction on clinical practice. (Of particular note is the fact that on early Toronto CCAC teleconferences, CCAC were recommending that nurses wear their N95 masks from home to home. This recommendation was withdrawn ***only*** when VON Canada and other provider groups expressed concern and outlined the clinical rationale for ***not*** carrying client care materials that cannot be cleaned from home to home.) Of greater concern, the PHD Infection Control representative was of the mind, after collaboration with CCAC staff, that masks could be left in the home and re-used on other visits. She did point out that the moisture resulting from sealing in a Ziploc bag could present a medium for growth, but suggested the bag be left slightly unsealed or that the mask be stored in a paper bag. Home care nurses have very little control over their environment when they are in the home, let alone when they are not in the home (e.g. a neighbour who just finished dialysis at Scarborough General fiddles with the bag and mask while the client is out of the room making coffee – only one of 1000's of potential scenarios). ***I understand the concern around cost of supplies, but if there is a clinical rationale for wearing a mask, then each nurse/PSW/Volunteer deserves to be confident about the integrity of the mask he/she is putting on***. Health Canada told me that even crushing compromises the effectiveness of a mask. I asked that this position be based on broad consultation and on as much evidence as possible before such supply decisions are made. ***What price can be placed on the death of a health care worker in the line of duty?***

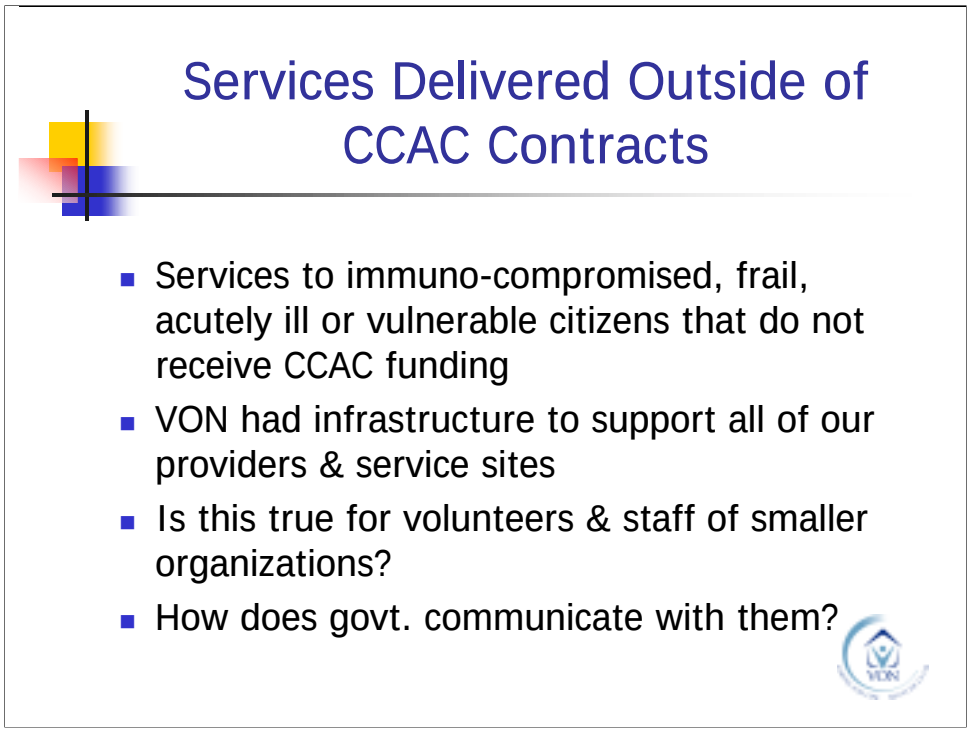


I sometimes wonder if the response time and fiscal disparities between hospital and home care sectors can be simply accounted for by our lack of visibility. You can see a hospital or LTC facility, but you don't see the critical mass of home and community care patients when you drive through urban and rural Ontario. They are behind closed doors.

Given the vulnerability and acuity of our patient load, it was very demoralizing at the beginning to discover that our staff would not be able to access equipment to protect themselves because suppliers across the country had been told they could only sell to the hospital sector. (In VON's internal debriefing, one branch stated "Discharging hospitals were supposed to send home 48 hours worth of protectice equipment for providers, buthtey were reluctant to do so, and the CCACs were reluctant to provide thses supplies as well.")

Staff that worked even 1 shift in a hospital was not allowed to work their other 9 shifts per fortnight in the community sector. *This created personal financial stress as well as staffing challenges in delivering service at a time when home care played a crucial role in keeping individuals at home and out of hospitals and LTC facilities.*

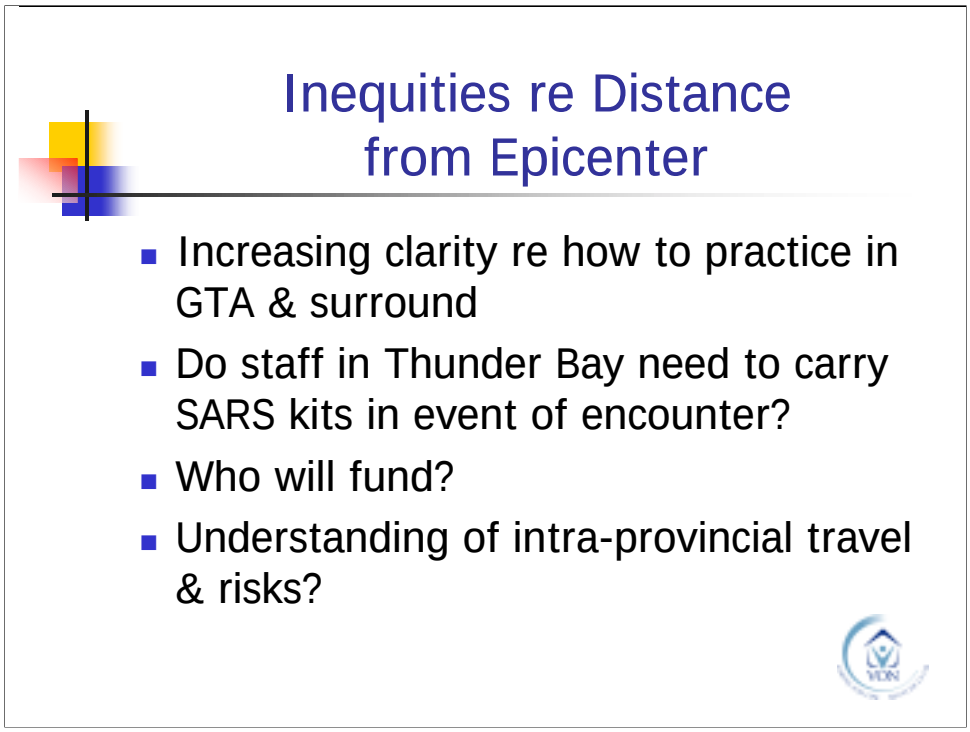
It felt like we were helping to hold up both ends of the health care facility continuum without support. More importantly, we worried about staff being a source of transmission in the community without knowledge and supplies to protect themselves and their patients.



Many home-based and community services to immuno-compromised, frail, vulnerable and ill citizens are delivered outside of CCAC funding. For example, VON offers a range of volunteer services such as Meals on Wheels, Adult Day Programs for Alzheimer's patients and Friendly Visiting. We also work with homeless populations. VON Canada had the infrastructure to support and prepare these providers as well, but I wonder if this was the case for many volunteers and staff of smaller organizations e.g. churches, hospices, shelters, etc.

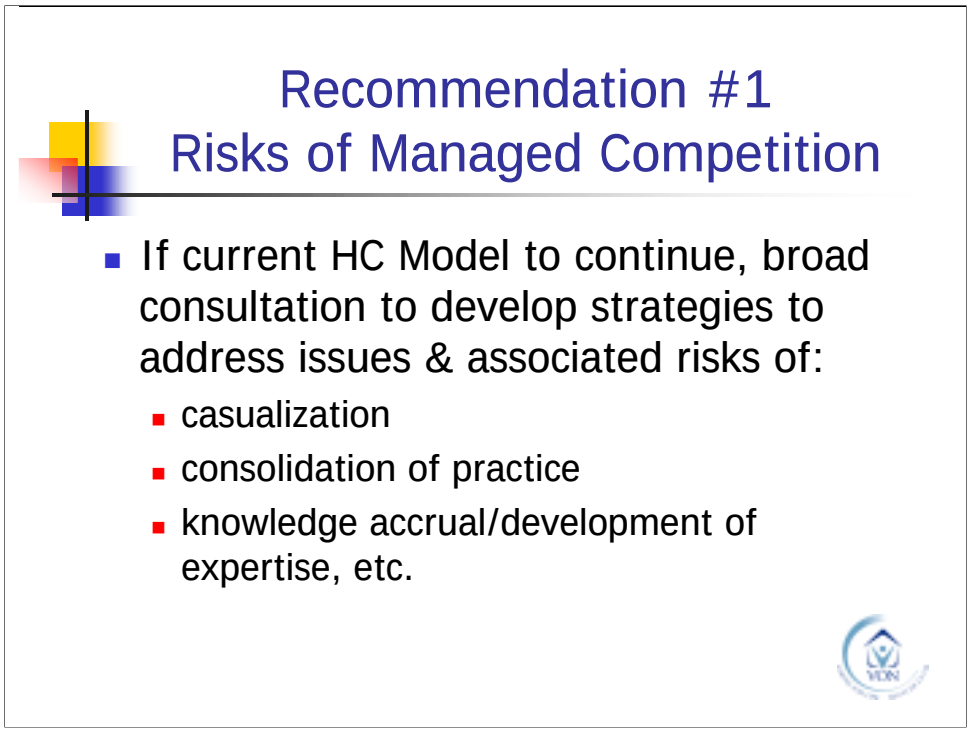
VON Canada had a communication infrastructure in place and within 24 hours was able to link its entire frontline management staff across the country via a List Serv and website to ensure everyone had SARS info in a timely fashion. There was a dedicated "SARS Point Person" at every branch. VON quickly built and maintained a website to provide easy access to WHO, Health Canada, POC and Public Health SARS resources as well as VON policy positions. National Clinical Staff remained on call 24/7. IT staff were able to support evenings and weekends to ensure current website postings. Teleconferences were held on a regular basis to ensure dynamic exchange of information.

National Clinical resources ensured our infection control guidelines/policies were current and evidence-based. It was easy to review with staff and then integrate the SARS practice guidelines as they evolved.



It became much more clear over time how to practice in the epicentre, but less so in other parts of the province. For example, did nurses in Thunder Bay need to carry SARS kits in the event of encountering a symptomatic patient in the home?

While CCACs in the epicentre were supporting supply costs for these kits, CCACs in other parts of the province were not. Just as people routinely travel from Asia to Toronto, people from northern Ontario routinely travel to Toronto for business, social and health care reasons. It seemed as if the further a VON branch was from the epicentre, the greater the variability in direction from Public Health Departments and CCACs. Branches farther away from the epicentre also reported decreased interest in POC directives in their communities and lack of support for supplying personal protective equipment (PPE) e.g. gowns, masks, goggles.



Minister Clement expressed surprise about the ratio of PT to FT nurses. RNAO reports that "in home care, 70% of nurses work part-time and casual as a result of the competitive bidding process which has encouraged lack of employment stability and lower overall compensation practices".

Think about it! How will a nurse ever get to consolidate practice or build expertise if he/she never gets to see the same patient over time and evaluate the outcomes of multidisciplinary interventions? How will a nurse ever get to build expertise if he/she rarely has access to an experienced nurse or manager. This is a particularly crucial matter in the community/home care sector where there is little direct supervision and no easy access to peer consultation. In the hospital or LTC facility, you can stick your head in another room or go to the nursing station to ask a senior nurse how to manage something. That doesn't happen when you practice in the isolation of the community and travel between clients.

There is absolutely no substitute for experiential learning, but systemic changes are required to help this happen in the community sector.

Recommendation #2
Support If Managed Competition

If current model is going to continue in HC sector, there need to be system supports within the HC/Community Sector to ensure all Service Providers Organizations, regardless of size or internal resources,

have access to same quality & degree of clinical support,

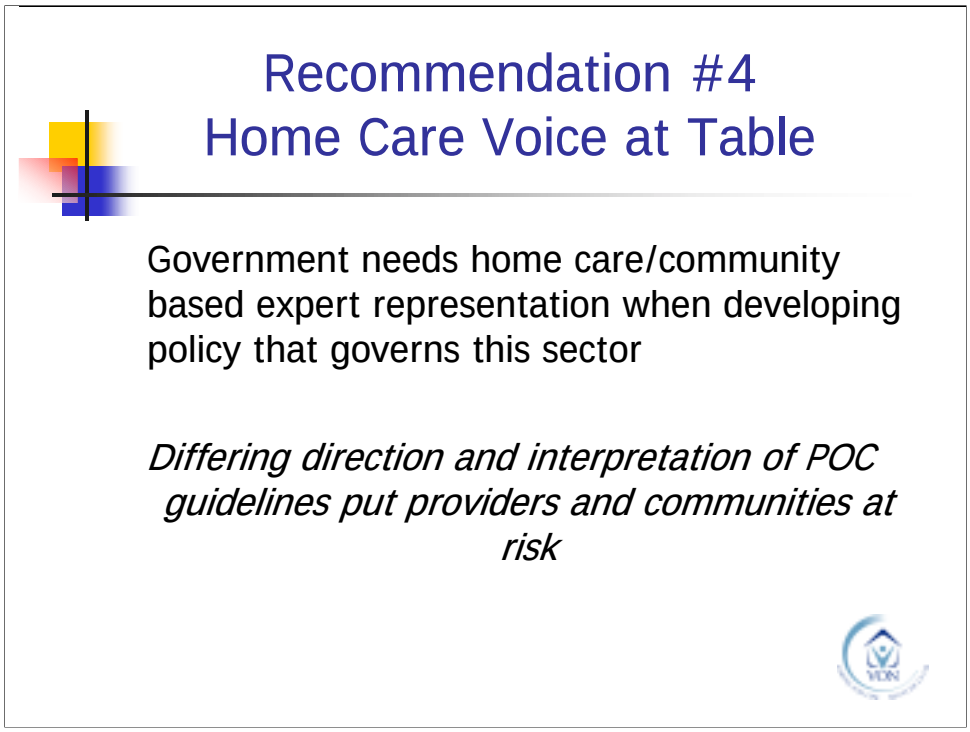
particularly Infectious Disease support

I am proud to say that Service Provider Organizations (SPO) never allowed the managed competition model to in any way inhibit the exchange of information during the SARS crisis. There was immediate and unspoken consensus about the need to pull together. SPOs consulted with one another re interpretation of POC guidelines and shared “best practices”.

Recommendation #3
Clinical Support under Managed Competition

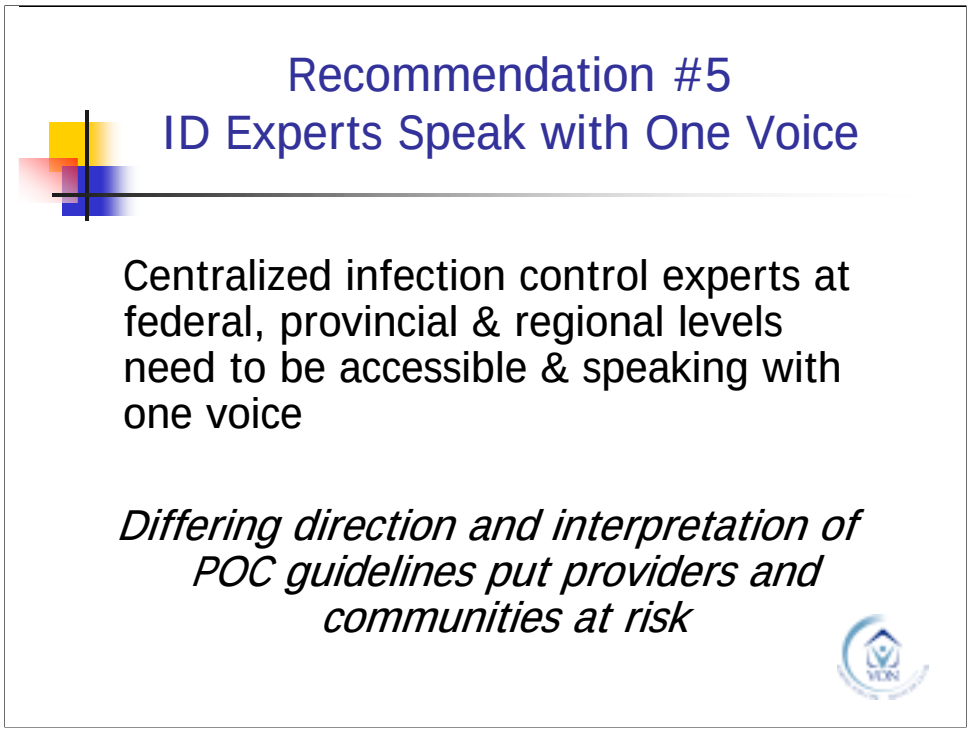
- Clinical support needs to be province-wide, not built into any single CCAC

Differing direction and interpretation of POC guidelines put providers and communities at risk

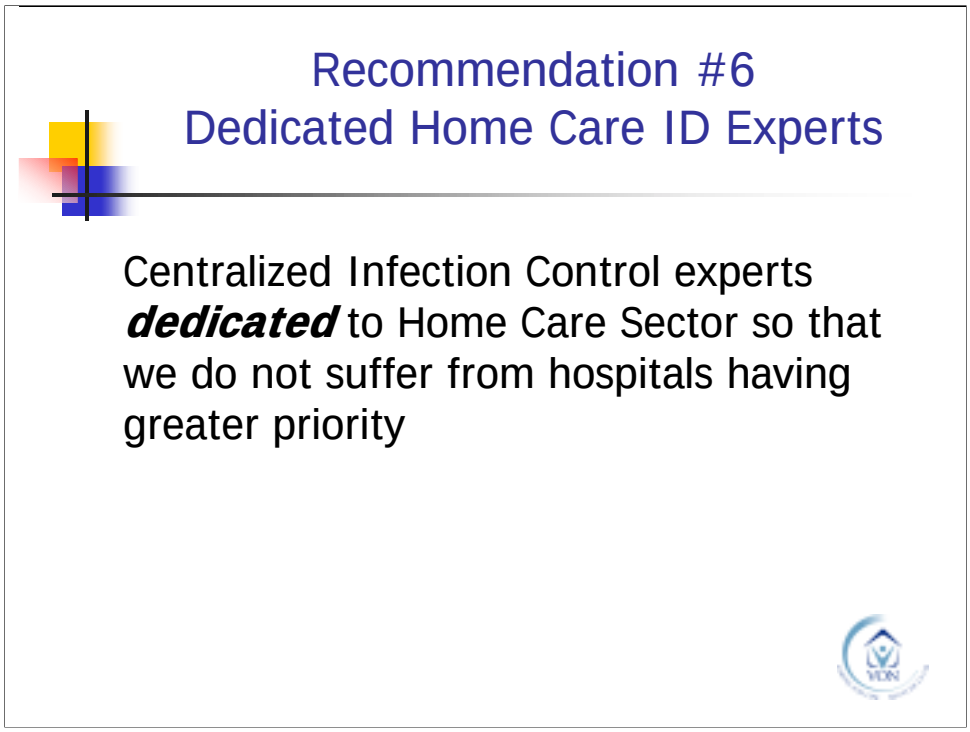


The best Home Care & Community experts are found in the Service Provider Organizations delivering Home and Community Care services throughout the province. VON Canada, along with other Home Care SPOs, has great expertise and broad experience to bring to policy development for this sector.

I ask that government include VON Canada in the planning and policy development for management of health care emergencies as they affect the home and community care sectors.



Accessibility is just as important as the consistency of message. Internal debriefing revealed that VON branches have built good relationships with both Public Health and hospitals in their regions in order to access expert advice on infectious diseases and their prevention and management. These ID experts can be very generous with their time. However, they are simply not available to us during a crisis when demands on them are excessive.



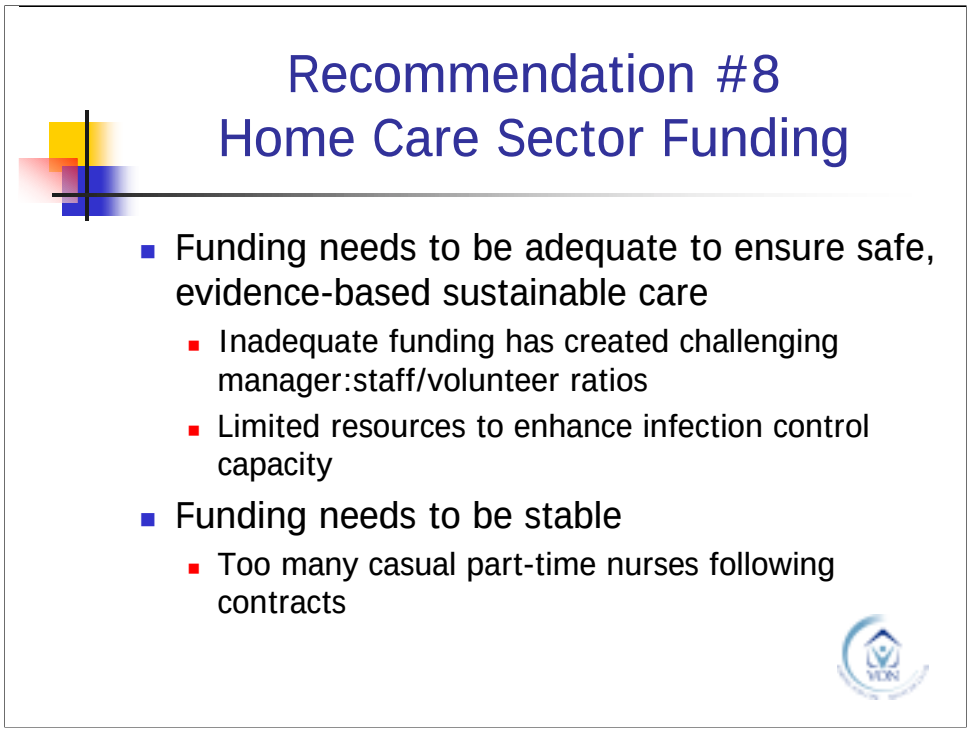
There needs to be government funded centralized Infection Control Experts dedicated to the Home Care sector so that the home care sector does not suffer from:

1. hospital or LTC facility issues having a greater priority
2. Public Health Departments providing community health advice without understanding the nature of "hospital-in-the-home" services.

Home Care experts can be working in parallel with hospital-based experts and PH experts and have parallel response times. There is no way to predict whether the next emergency will have a greater risk of spread in the community or institutional sectors.

Recommendation #7 “Trusting the Advice”

- Infection Control Experts need to be positioned in the system so that they:
  - do not HAVE a vested interest in the cost of supplies
  - Cannot be influenced to make supply decisions based on the cost to other government programs



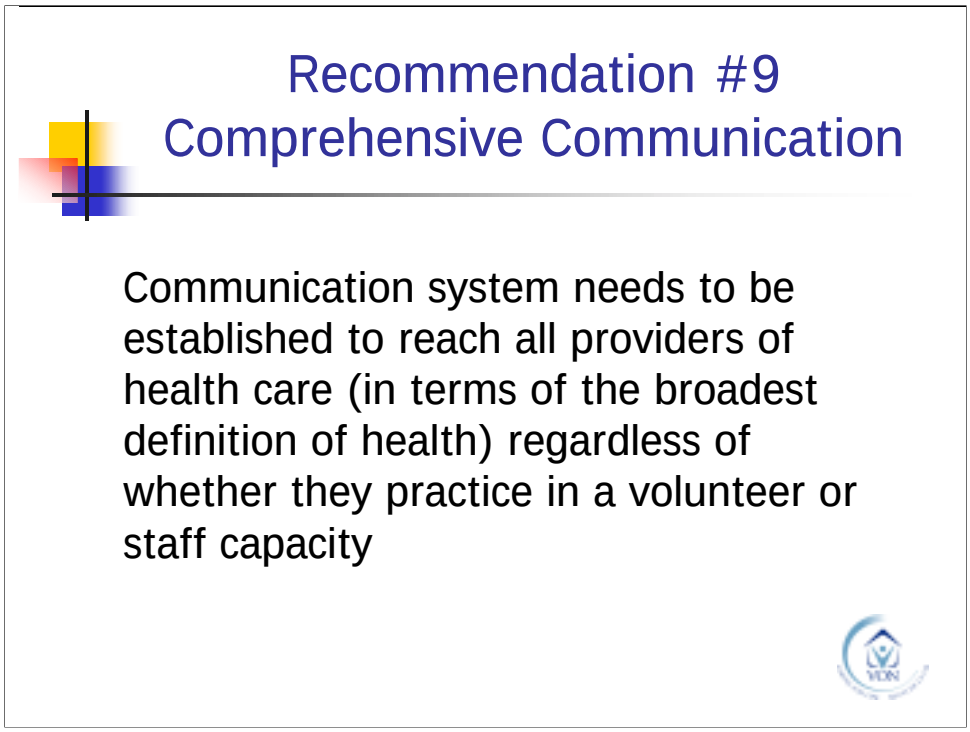
Reducing funding in any given sector usually means a decrease in the number of managers and an increase in the manager to staff or volunteer ratio. The amount of time a manager needs to spend orienting, providing ongoing in-service, and evaluating infection control practices varies based on the level of provider e.g. professional versus para-professional, and the experience and expertise of the individual provider. It is also more time-consuming to supervise "offsite" staff.

There are limited resources to enhance infection control capacity in the Home & Community care sector. The Home and Community Care sector needs to enhance its infection prevention and control capacity. The Ontario government has made $ available to support the professional development of nurses through RNAO. Up to $1500 per year is available per nurse. There are also Fellowships worth as much as $12000 dollars to promote best practices.

It would be helpful to see government funds dedicated to gaining Infection Control expertise in the Home& Community Care sector for professionals, para-professionals and volunteers. I ask that there be funds allocated to developing a "best practice" guideline for Infection Prevention and Control in the Home/Community Care sector. It would also be helpful to have government help to build infection prevention and control capacity in the Home and Community Care sector by paying salaries of nurses to attend courses on IP&C, develop standardized courses for all groups of health care service providers, and more importantly, make them available to all service providers through web-based learning.

Without stable funding, it is difficult to offer full-time positions and nurses have to move from employer to employer as CCACs award contracts to different providers. They also have to work for multiple providers to cobble together fulltime hours.

No matter how hard a home care provider works to build capacity, it can be lost in the stroke of a pen when a CCAC awards its contract elsewhere.



At a recent conference on Patient Safety and Disclosure of Error, which is crucial to quality improvement, many participants noted that they had not been informed of coroner recommendations for some time. One of the speakers was a provincial coroner. He stated that the government had stopped mailing out coroner's findings and recommendations because of the cost. I can remember receiving a Coroner's Report in the mail years ago. This was followed up some months later with a demand to report back on how VON had implemented the recommendations. This ensured the the quality improvement loop was closed. Think of what it costs to hold an inquest and then not have any changes result because of the cost of dissemination!

We have the technology. I would suggest that the government adopt a strategy similar to that of VON e.g. web-based announcements coupled with a comprehensive e-mail distribution list of all those that "need to know" about any health and safety issue. A "point person" identified at every organization ensures the ability to quickly dialogue with key individuals about any given emergency. It is too late to start building a communication system once an emergency strikes.

Recommendation #10
Ensuring Safety/Minimizing Risk

A means of measuring infection prevention and control knowledge & practices, regardless of size or “distance from formal delivery systems” of all service provider organizations

To ensure safety and minimize risk, the government needs a means of ….

Summary Recommendations

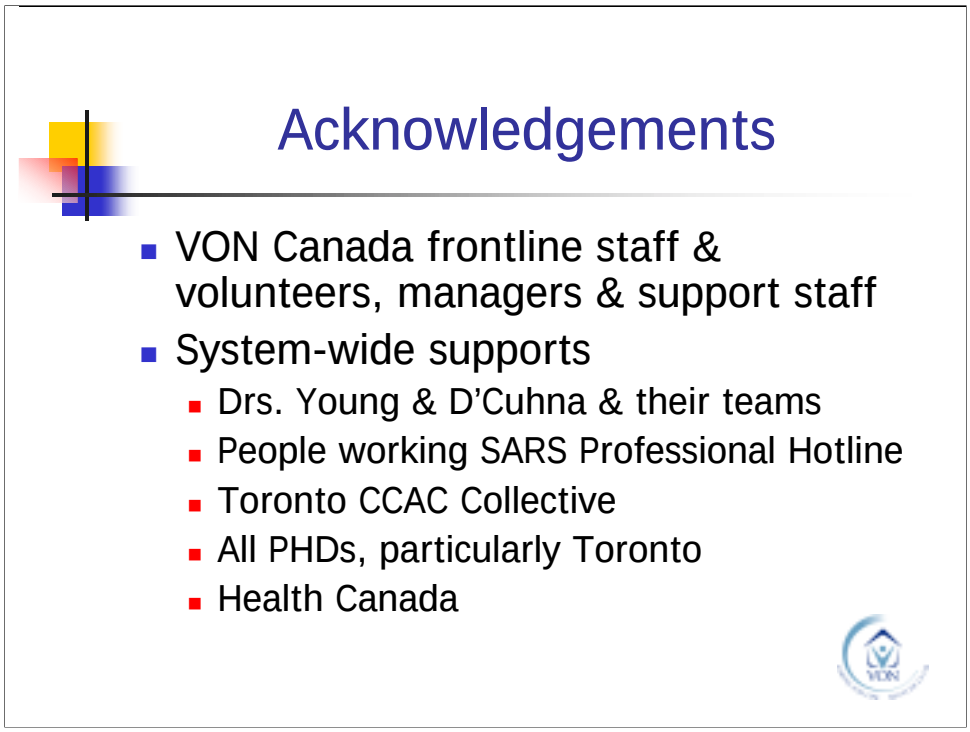
- Federal, provincial, regional government ID disease experts need to speak with one voice
- Voice needs to represent Home Care sector
- Home Care access to ID expertise needs to be as timely as other sectors
- Home Care Sector needs adequate funding to ensure safe practice

Federal, provincial, regional government ID disease experts need to speak with one voice

Voice needs to ***BOTH represent and INCLUDE*** the Home Care sector

Home Care access to ID expertise needs to be as timely as other sectors

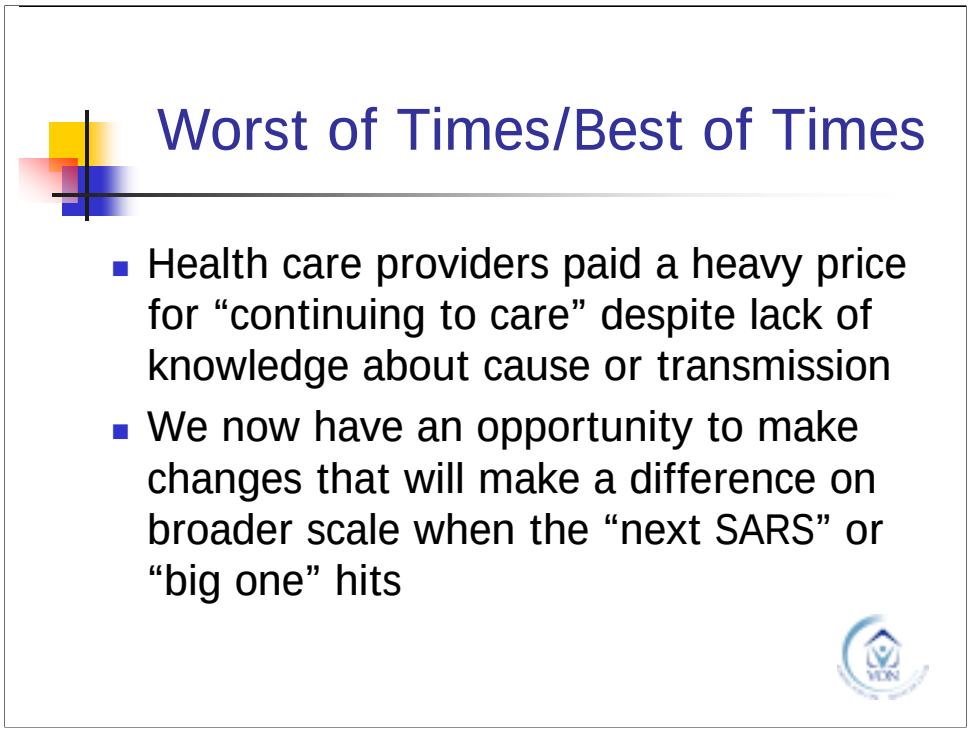
Home Care Sector needs adequate funding to ensure safe practice



I want to acknowledge and celebrate VON Canada frontline staff & volunteers, managers & support staff. I also want to acknowledge the system supports that allowed us to do our jobs as safely and effectively as possible…

Despite systemic failures, I don't believe there was one person who wasn't working beyond their capacity to ensure the best care possible for all citizens and to avoid the devastating loss of life that ensued.

VON Canada debriefing reveals that staff viewed SARS as a challenge that stretched all of our personal and professional resources, but that as a collective team, we rose to the occasion.



Health care providers, particularly in the hospital sector on this occasion, paid a heavy price for “continuing to care” despite lack of knowledge about cause or transmission.

Despite that fact, the SARS Emergency was an amazing opportunity to be part of a community of committed individuals pulling together as one for the health of Canadians

***I can’t help but think, “the best is yet to come” as the SARS experience gets debriefed** and we can identify system changes to prepare more effectively for the next emergency.*

If any good is to come from the devastating losses at all, recommendations must be implemented.

I can’t see the value of finger pointing. I am hoping that a reasoned systemic review will result in the kind of changes that will truly make a sustained difference.

Thank you for the opportunity to participate in this process.