

Helping Bridge the Gaps:

***Annual Report of the
Alberta Health Advocate
2014-2015***

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The Office of the Alberta Health Advocates (OAHA) is part of the network of concerns and complaint resolution processes within Alberta's health services environment.

Established in 2014, the OAHA assists Albertans in dealing with their concerns about services impacting their health and in becoming empowered and effective advocates in their own health and health care. The OAHA also supports and advocates for a system that is responsive and accountable to the people being served.

The OAHA includes the Health Advocate, the Seniors' Advocate and the Mental Health Patient Advocate. The Health Advocate and Seniors' Advocate started with a reporting relationship to the Minister of Health but with the creation of Alberta Seniors in the Fall of 2014, the Seniors' Advocate now reports to the Minister of Seniors. The Seniors' Advocate has remained a part of the OAHA.

NOTE: The Mental Health Patient Advocate is reporting separately on activities for 2014-2015.

Letter to the Minister of Health

October 30, 2015

The Honorable Sarah Hoffman
Minister of Health
423 Legislature Building
10800 97 Avenue
Edmonton, AB Canada T5K 2B6

Dear Minister Hoffman:

In accordance with the provisions of section 6(1) of the *Alberta Health Act*, it is my duty and privilege to submit to you the first annual report summarizing the activities of the Health Advocate and the Seniors' Advocate for the period from January 1, 2014 to April 1, 2015.

Respectfully submitted,



Deborah E. Prowse, Q.C.
Alberta Health Advocate,
Interim Seniors' Advocate

Message from the Alberta Health Advocate and Interim Seniors' Advocate



"Patients and their families are at the center of what we do"

The Office of the Alberta Health Advocates is the first of its kind in Canada and breaking new ground. So when the doors opened on April 1, 2014, we didn't know what issues Albertans would bring to our attention. It didn't take long to find out.

Part of our mandate as an office is to help people find their way to the appropriate place to address their concerns and we've been able to connect people to the right resources. We also have been able to listen hard and help concerned Albertans with working through their issues so that they know what they want and need to do.

We have also found that people aren't always able to resolve their issues despite the very good complaint resolution processes set up by professional colleges, Alberta Health Services and other organizations. Their problems often are complex and can spill over multiple jurisdictions. Sometimes there isn't a good fit anywhere and people feel frustrated and let down by the processes they looked to for help.

We are also finding that people can go through all the right steps they are told they need to take, but at the end of the day, still feel that they have not been heard. Albertans are looking for something more. They would like to see a coordinated approach that takes into account their circumstances. Sometimes they would like someone to mediate between them and several different

Summary of Activities

*1222 Albertans served
54 Presentations
94 Consultations*

organizations. At other times, they just want someone to acknowledge what they've gone through and ensure that 'the system' hears about their experiences and looks for ways to change things for the better.

People also call to tell us about the excellent experiences they have had. We have heard about good communications, services that supported them and their families when they were in crisis, and high quality patient/family-centered care. They call in the hopes that others in the system can learn from these outstanding practices so everyone's care improves.

Starting up the OAHA has been a challenging and worthwhile process and I'm honoured to present its first annual report covering January 1, 2014 to April 1, 2015. I joined the Office on July 1st, 2014, to continue the work Mary Marshall began as Alberta's first Interim Health Advocate. Her leadership in building the foundation for an integrated approach to moving forward has set the stage for everything that has since been done. Thank you as well to John Cabral, who took on the role of Alberta's first Seniors' Advocate on an interim basis. Since taking on this role in early 2015, I have been fortunate to be able to build on the work he started.

We've just begun. Coordinating the mandates of the Health Advocate, Seniors' Advocate and Mental Health Patient Advocate is an ongoing learning experience, but the benefits of being able to help people without jurisdictional barriers between the Advocates is worth the work. We need to continue to strengthen our relationships with other stakeholders in the system and give them feedback on Albertans' concerns.

I also look forward to bringing to life the Health Charter, which sets out the expectations when Albertans interact with the health care system. As we gain experience and listen to the concerns Albertans are bringing to us, we will

work on ensuring that our next few years are guided by our mission, vision and values.

It's been a busy year. Our office would not have made the progress we have over the last year without the support of passionate and committed staff that weren't afraid of the challenges of a start-up. At the beginning our staff was seconded from other areas of government and I want to also thank their co-workers who covered for them while they worked to help us out. Thank you as well to the dedicated people at Alberta Health who helped launch the OAHA. And, in addition, to the Interim Advocates, Mary Marshall and John Cabral, the Mental Health Patient Advocate and her staff, I want to thank the many Albertans who have called our office who renew our conviction and passion every day.

I look forward to continue to work with Albertans, the Advocates and our staff to support the people we serve, bridge gaps and help improve Alberta's health care system.



Respectfully,

Deborah E. Prowse, Q.C.

Alberta Health Advocate and Interim Seniors' Advocate

Alberta Health Charter

The new [Alberta Health Act \(2014\)](#) requires the province to have a Health Charter. [Alberta's Health Charter](#) sets out key values and aims for Alberta's health system and the roles and responsibilities of patients and providers within the health system. It is intended to guide the actions of health service organizations, providers, patients and government in the broader health system, both publicly funded and those services purchased through insurance or directly by individuals. The Alberta Health Advocate uses the Health Charter as a lens to consider concerns and complaints brought to its attention by Albertans.

The concept of a charter was first proposed in 2010 by the stakeholder committee appointed to make recommendations on new health legislation for Alberta. The idea of a patient charter was discussed with Albertans during a 23 community consultation process. What Albertans said at the time is that the concept of health is broader than someone receiving services as a patient: Health is about the overall wellness of people and involves Albertans, health professionals, organizations delivering care and services, and the Government of Alberta ([Putting People First, Part One, Recommendations for an Alberta Health Act, 2010](#)). It specifically embraces that health, wellness and quality of life of Albertans are influenced by their economic, social, cultural, physical and spiritual context. Based on that input, the concept of a patient charter was expanded to encompass the broader notion of health.

Alberta's first Health Charter is aligned with the [Alberta Quality Matrix for Health](#). It also speaks to issues of respect and dignity, participation, collaboration and information sharing - key tenets of patient family centered care.

The Health Charter is intended to be a living document. As we gain experience with the Health Charter, we expect that what the Health Charter contains will evolve as we better understand what it means to have a Health Charter and how it can help people, providers and government understand their roles and responsibilities.

Alberta Health Charter

When I interact with the health system, I expect that I will:

- Have my health status, social and economic circumstances, and personal beliefs and values acknowledged
- Be treated with respect and dignity
- Have access to team-based primary care services
- Have the confidentiality and privacy of my health information respected
- Be informed in ways that I understand so that I may make informed decisions about my health, health care and treatment
- Be able to participate fully in my health and health care
- Be supported through my care journey and helped to find and access the health services and care that I require
- Receive information on the health system and education about healthy living and wellness
- Have timely and reasonable access to safe, high quality health services and care
- Have timely and reasonable access to my personal health information
- Have the opportunity to raise concerns and receive a timely response to my concerns, without fear of retribution or an impact on my health services and care

Taking my circumstances into account and to the best of my abilities, when I interact with the health system, I understand that I will be asked to:

- Respect the rights of other patients and health providers
- Ask questions and work with providers to understand the information I am being provided
- Demonstrate that I, or my guardian and/or caregivers, understand the care plan we have developed together and that steps are being taken to follow the plan
- Treat health services as a valuable public resource
- Learn how to better access health services
- Make healthy choices in my life

As I work to be a healthy citizen within Alberta, I expect that:

- When economic, fiscal and social policies are being developed by the Alberta government, the impact of those policies on public health, wellness and prevention will be considered and steps taken to ensure that public policy is healthy policy.

Order in Council, March 20, 2014

About the Office of the Alberta Health Advocates

When people have had a disappointing experience or want to talk to someone about the challenges they are having with services and care, the OAHA is there to listen to their concerns and to assist them in determining their best course of action.

Background

Our health system should always be about responding to the needs of people using the system and their families. When the new *Alberta Health Act* came into force on January 1, 2014, it set out Alberta's commitment to the principles of the [Canada Health Act](#) and called for the adoption of a health charter and the appointment of a health advocate. At the same time, the decision was made to create a Seniors' Advocate position, which expanded the scope of the OAHA to include services to seniors that go beyond those within the health system.

The new Advocates came together with the long-standing Mental Health Patient Advocate to form the Office of the Alberta Health Advocates (OAHA). The OAHA was established to help people:

- Navigate the health system and services to seniors,
- Better deal with health system issues and challenges
- Understand the rights, roles, responsibilities of individuals, providers and organizations and what they can expect from each other.

Together, the organization of the OAHA makes it possible to respond to the health, mental health and seniors needs of Albertans in a comprehensive and seamless manner.

Our Vision

The OAHA envisions an integrated and responsive system that empowers and supports Albertans as full participants

"I believe the most useful knowledge about human behavior is based on people's lived experiences."

Brene Brown

in their care and fairly addresses their concerns about services that impact health.

Our Mission

The OAHA promotes self-advocacy and assists Albertans in dealing with their concerns about services impacting their health and becoming empowered and effective advocates.

Our Values

Values are the key characteristics of an organization that guide its actions. Values describe the personality of the organization – how it would act if it was a person.

The values of the OAHA are:

- **Respect** – The OAHA respects the perspective of others and how they feel about what has happened or is happening to them.
- **Integrity** – The OAHA strives to act in ways that are just, ethical, transparent, honest and fair.
- **Compassion** - The OAHA identifies with the concerns of individuals who are experiencing problems in their interactions with the health and seniors' services system. The OAHA will listen and act with empathy for the concerns of others.
- **Engagement** – The OAHA actively listens to people and stakeholders, working with them to understand relationships and concerns; helping find resolution in the fullest way possible.
- **Excellence** – The OAHA works to embed quality and a continuously improving system of excellence in all that it does.

Health Advocate Mandate and Functions

The introduction of Alberta's Health Charter and the appointment of the Health Advocate and Seniors' Advocate are foundational developments in the ongoing evolution of Alberta's health and seniors' services. The role of the OAHA is unique in that its mandate encompasses the breadth of the health system not that of any single profession or organization. The OAHA presents a seamless service as the Advocates work together to serve Albertans whose interests can fall under the mandate of one or all three Advocates. The OAHA receives calls and inquiries from Albertans about their health care journey and experience. We work to translate the information gathered into improvements to the quality and safety of the Alberta health care, mental health and seniors' services.

Daily activities carried out by the Health Advocate are guided by the core legislated functions described in the *Alberta Health Act* and the [Health Advocate Regulation](#). Often, elements of these functions are present in the contact with Health Advocate staff. This is especially true when individuals present with highly complex conditions and experiences.

The four legislated functions are:

Review

In cases where no other dispute resolution process exists, the Health Advocate may conduct reviews, with or without a complaint, into situations where a person has allegedly failed to act in a manner consistent with the Health Charter.

Assist

When an Albertan contacts the office, the person is connected with a Health Advocate Representative,

"People don't always need advice. Sometimes, all they need is a hand to hold, an ear to listen, and a heart to understand them."

Unknown

who listens to understand the individual's concern. They will together determine the issue(s), and then the Health Advocate Representative will conduct any necessary research and inquiry to learn more about all aspects of the concern. The Health Advocate Representative will then work with the individual to develop a plan of action and provide support to the individual so that they can act on their own behalf when a referral is made to another complaint process, program or service.

Navigate

The health service system is complex and difficult to understand, particularly for those who are suffering, in pain and are vulnerable. The Health Advocate assists individuals to find their way to the appropriate health services, health related programs, and resources to meet their expressed needs.

Educate and Inform

The Alberta Health Charter is an aspirational document, setting out the expectations for interactions among patients, health providers and health service organizations. The Health Advocate provides education about the Health Charter and how it applies to Alberta's health service system. The Health Advocate aims to use every interaction between staff and Albertans as an opportunity to educate people on roles, responsibilities and expectations with the system.

Seniors' Advocate Mandate and Functions

The Seniors' Advocate supports seniors, their families and caregivers by providing them with public education, information, navigation and referral services. The first Seniors' Advocate, John Cabral, was appointed in 2014 and initially reported to the Minister of Health. When Alberta Seniors was created in the Fall of 2014, the Seniors' Advocate began reporting to the Minister of

Seniors. Effective January 1, 2015, the Health Advocate was also appointed as the Interim Seniors Advocate by Ministerial Order for a one (1) year period there by keeping the role functionally in the OAHA. The staff of the Health Advocate serves those who call with respect to seniors services.

As set out by Ministerial Order, the mandate of the Seniors' Advocate includes:

- Providing education about the rights, interests and needs of seniors including matters such as elder abuse, aging in place, age friendly communities, older workers and ageism to Albertans and stakeholders
- Providing information and referrals to seniors and their families regarding government-funded seniors health, continuing care and social support programs and services;
- Engaging with seniors and families on issues affecting seniors;
- Requesting the inspection of provincial facilities, including, supportive living accommodation, long-term care accommodation, auxiliary hospital, nursing home or any place within Alberta Health Service's jurisdiction;
- Referring reports of abuse from a publically funded service provider to an investigator under the *Protections for Persons in Care Act*;
- Reporting to the Minister of Seniors on current trends, issues and potential improvements.

The Interim Seniors' Advocate has met with the Seniors Advisory Council for Alberta (SACA). This Council is responsible for advising the province on matters relating to Alberta's seniors. The Council gathers information by consulting with older Albertans and seniors' organizations in communities across the province. It is anticipated that

there will be a strategic relationship between the Seniors' Advocate and SACA in the future.

Experiences in Our Health Services System

Each day, thousands of interactions take place between Albertans and the Alberta health system. While many Albertans are well served and report a positive experience in their care, there are times the experience does not go as expected and a patient, family member or caregiver is left with a question, concern or complaint that they may not know how to resolve.

We have learned that these concerns arising out of health care are complex. It is apparent from the number of Albertans who have contacted our office in the past year, that there is a role for the OAHA to play in helping people define the issues of their health care experience. There is also a role in offering support to find resolution. In turn, the system needs to hear about these situations to ensure it is responsive to the needs of Albertans and leads in providing safe patient or client-focused, high quality health and seniors services.

Since opening its doors, Albertans have been calling the Health Advocate and the Seniors' Advocate with a wide variety of their questions and concerns. Everyone's story of their experience is unique, but themes are emerging.

In many ways the stories heard by the OAHA parallel the key factors influencing satisfaction with health care services identified by the Health Quality Council of Alberta: the quality of the service, their access to the service, and how healthcare professionals coordinate their efforts to meet patient needs ([Health Quality Council of Alberta, 2015](#)). What also comes through is the human impact that health and seniors services can have as they experience these systems. When people tell us their stories, we often hear the emotional, financial and social tolls their health care experiences have taken on them and their families. It is emotionally difficult to be a patient, to be in care, or to support someone as they journey through

"When you talk you are only repeating what you already know. But if you listen, you may learn something new."

Dalai Lama

the system. We hear from Albertans that health care is an emotional journey.

The Health Charter sets out for people the expectations they should reasonably have for how care is provided. When many people call, their concerns relate back to the provisions within the Health Charter, including the ability to access care, quality and safety, respect, access to information and the ability to take an active role in their care. The issues demonstrate that there is a gap between the people's expectations and their experiences.

Listening and Learning

Finding Resolution

There are many high quality complaint resolution processes in the system that operates uniquely within their own limited jurisdiction and practice. People find they may be dealing with a number of different agencies and go through all the processes in their attempt to address a concern, but often, it doesn't add up to something they can identify as resolution. Furthermore, there isn't connection amongst the processes or a shared approach by the organizations. This is due sometimes to legislated privacy provisions and at other times due to jurisdictional differences. While the complainant remains the same, the organizations involved deal with the complaint solely from their own perspective. People report they have felt the burden of coordinating these various processes, all the while, often left feeling unheard. The OAHA has been able to assist these situations by bridging communication gaps and making appropriate connections with appropriate resources where possible.

Finding Support

The Health Advocate has heard that people need support and they seek someone to listen and understand their experience. In many of the calls received, people express how they feel disappointed that the system doesn't work as an integrated structure with shared information and seamless transitions throughout the continuum of care. They expect to have clear communication throughout their care journey, whether in the community or acute care settings, Albertans expect someone to take an interest in their concerns and follow through in a timely manner.

"I'm calling to say how grateful we are for the time you gave us. You provided so much detailed information and direction about how we could get supports in place to manage our daughter's physical and mental illness. We have followed through with your suggestions and it has completely turned our world around for the better."

Client

"You gave me hope and a plan."

Client

They expect to participate in discussions about their care or the care of a family member. Instead, they sometimes experience a lack of continuity in their journey, including missed referrals, barriers to care and a lack of resources. When this occurs, Albertans come to expect more from a health system they greatly value.

The Health Advocate is finding that people need emotional support in their health care journey. They're looking for someone who can listen, validate and understand the impact of what they have experienced. The journey through the health and seniors' service systems can be lonely, confusing and even traumatic. While health service providers may deal with many people facing the same issues each day, for the individual, it's a new experience that is unique to them. The OAHA is able to provide support and empowerment for the journey and is able to assist with bridging some of the information and communication gaps that Albertans may experience

Sharing Stories

No one wants to find out that their condition could have been diagnosed earlier if all the aspects of their symptoms and test results had been looked at differently or sooner. When people call to tell the Health Advocate their story about a missed or delayed diagnosis, it's often to talk about lessons that go beyond the treatment regime. People want their experience to count for something; they want it to be a learning experience that gets tied to quality improvement. They ask that their story be captured and shared in conversations with stakeholders and in the presentations and reports carried out by the Health Advocate.

Bridging Communication

Complaints about disrespectful treatment are often linked to poor communication between patients, families and providers. People feel their concerns have been dismissed or ignored and information had not been provided in ways that they can understand. Respect and dignity is also related to a lack of transparency and due process in decision making, particularly around assessment processes, placement decisions, available diagnostics and treatment, plans of care,

"When we deny the story, it defines us. When we own the story, we can write a brave new ending."

Brene Brown

"Thank you for being the first person to listen to the whole story for the first time."

Client

access to information and correction of information in medical records.

Some of the most challenging conflict issues arise out of communication breakdown, sometimes leaving friends and family members restricted in visitation or banned from health facilities. Conflict and negative emotions can interfere with the interactions between patients and providers, affecting trust. This has resulted in requests for a fair and transparent process when people are banned. The Health Advocate is hoping to be able to assist in addressing through collaboration with the parties involved.

Freedom to Comment

In health care, people rely on receiving the services they or a loved one need. When a concern about quality and safety of care arises, they don't always feel safe in asking questions or raising the concern without fear of retaliation. People have expressed a feeling of powerlessness in the relationship they have with providers, rather than a true partnership in their health care. The Health Advocate is planning to address this type of concern through education of Albertans and providers on how to raise concerns, build partnerships in care and positively advocate for your own care.

Gaining Access

Albertans expect to get the care they need when they need it and in a location that is convenient to them. The Health Advocate has heard from many people who feel frustrated by long wait lists for such health care services as diagnostics, appointments with medical specialists including mental health resources, treatments such as surgery, and rehabilitation services. The Health Advocate has heard about the impact that extensive wait times has on people's quality of life. Over the course of the wait, people have shared that they lose their jobs because they can't work in pain, suffer marital breakdowns and experience mental illness or addiction. The Health Advocate Representatives work with people to ensure their health status has been accurately provided to the physicians responsible for determining the priority assessments and to ensure people are able to find

"Your thoughtful questions and tips made me think more and has given me the confidence to go on my own. Thank you."

Client

all of the resources available to assist them during the wait.

Seniors' Issues

Issues raised with the Seniors' Advocate include concerns about finding and accessing appropriate housing, home care and home support services to assist a person to remain independent in their community, financial issues related to government programs and transportation. People have shared their concerns about the financial costs of health care as they or a family member ages or becomes ill. Generally, families are not prepared for the financial demand of health care and expressed concern of the increasing financial costs of health services. They are concerned about the availability of health services; such as the number of continuing care beds, now and into the future as the Alberta population continues to age. The OAHA has also heard about issues regarding access to government programs, including transitioning from coverage under Assured Income for the Severely Handicapped (AISH) to the Alberta Seniors Benefit program. The office is also hearing of many instances where programs are confusing or coverage is inconsistent.

The staff of the OAHA is able to provide information about various programs and find the resources to support Albertans. Our staff is constantly seeking out available services and workers to ensure there is appropriate and efficient case management of the many services some people need to remain in the community or maintain their quality of life.

"I appreciate the time you have spent talking with me about the best ways to support my sister who is taking care of two elderly family members, working full time and feeling completely burnt out."

Client

As the baby boomers get older, the aging of the population in Alberta is expected to accelerate until 2030, when the last of that group reaches the age of 65. The total number of people aged 65 and over is expected to more than double, resulting in 1.18 million

Statistics Canada, 2014 and Alberta Treasury Board and Finance, 2015

Milestones

Over the course of the inaugural year, the Health Advocate has worked to establish the OAHA. This has included everything from ordering phones to hiring staff and establishing relationships with our stakeholders, including patient and seniors groups, professional colleges, Alberta Health Services and other parts of the Government of Alberta involved in providing health and senior services. The door is open, the phones are being answered and most importantly, Albertans are reaching out to the OAHA and sharing their experiences and seeking our assistance. All of these milestones are foundational and fundamental to becoming an autonomous and fully operational organization able to serve Albertans.

Opening Our Door

The OAHA opened to the Alberta public on April 1, 2014. At that time, Mary Marshall, Interim Health Advocate, was joined by Carol Robertson Baker, then Interim Mental Health Patient Advocate and John Cabral, Interim Senior's Advocate.

Under the leadership of Ms. Marshall, and with support from temporary staffing resources from a variety of government departments, the OAHA began receiving calls and correspondence from Albertans. At the same time, work continued on building operational infrastructure, including space and staffing.

During Ms. Marshall's tenure, her work focused on three areas: operationalizing the OAHA; supporting the Government of Alberta's consultation on the draft Health Advocate Regulation and draft Alberta Health Charter; and engaging with Albertans and stakeholders on the Health Charter and role of the Health Advocate, including education and public awareness.

Staffing the OAHA

The Health Advocate has administrative oversight over the OAHA and was charged with developing an organizational structure to support the work of the Health Advocate, Seniors' Advocate and the Mental Health Patient Advocate. In May 2014, four Advocate Representative staff joined the OAHA, complimenting the Advocates and the two existing Patient Rights Advocates. The staff of the OAHA has worked hard over the last year to carry out the legislated mandate while responding to Albertans



Front row (left to right): Deborah E. Prowse, Health Advocate and Interim Seniors' Advocate; Lisa Poholko, Health Advocate Representative; Wendy Armstrong, Health Advocate Representative; Back row (left to right): Jody-Lee Farrah, Manager Analysis and Investigations; Lorraine D'Sylva, Office Administrator; Sandi L. Jones, Seniors' Advocate Representative

Establishing Our Office

In order to operationalize its role, the Health Advocate held facilitated brainstorming discussions with the OAHA team to develop the foundational cornerstones of the OAHA, including its vision, mission and values. These have become the foundation for the strategic, operations and performance plans. The development of these plans has been an important part of becoming fully operational and providing direction, guidance and support for the OAHA's day-to-day activities.

The work of the OAHA requires skills set in listening, support, investigation and conflict management. In order to better support the provision of services, all staff members successfully completed, *Fundamentals of Mediation*, a training course (40 hours) equipping them with enhanced communication, negotiation and third-party resolution skills.

Supporting the Government of Alberta Consultation

On January 30, 2014, Alberta Health released a draft Health Advocate Regulation and draft Health Charter for consultation by the department and supported by the Interim Health Advocate. During the comment period, the Interim Health Advocate met with a wide variety of organizations to inform them about the governing legislation and draft Health Charter and encouraged them to participate. These organizations included professional groups, health organizations, patient groups and members of the public. The OAHA opened April 1, 2014 under the authority of the Regulation as released for consultation.

Concerns and comments made by stakeholders in the system included questions around the referral of complaints to professional colleges, role clarity between the three Advocates, and access to informal resolution mechanisms such as mediation to resolve complaints without conducting a formal review. Other organizations and individuals relayed concerns about the mandate and structure of the Health Advocate, including the Advocate's reporting relationship to the Minister of Health.

A priority for the Health Advocate in the 2015-16 fiscal years will be to reflect on the work of the Health Advocate and make recommendations to ensure the Regulation fully supports the work of the OAHA in addressing the concerns brought forward by Albertans and bridging gaps in the system.

Building Relationships

When a new organization is created, there is often a period of ambiguity and boundary concerns as the organization moves from a conceptual to operational state. In order to address this, the Health Advocate has

worked to connect with health system stakeholders and build collaborative relationships and mechanisms for working together when clients and patients approach the OAHA with concerns. Some of the key stakeholders include:

- Health Quality Council of Alberta (HQCA)
- Alberta Health
- Alberta Seniors
- Alberta Health Services
- Covenant Health
- Regulated health professional colleges
- Community organizations

Creating Awareness

The creation of the Health Advocate and the Health Charter under the *Alberta Health Act* is an innovative approach intended to provide a voice for patients to contribute to improvements in the health service system. A new model for Canada, it has been met with a great deal of interest from Albertans and organizations from across Canada. In response, the Health Advocate has made formal presentations, participated in expert panels, consulted with groups and educated individual Albertans on the role of the Health Advocate, the application of the Health Charter, and health system issues of importance to Albertans, including wait times, out-of-province coverage, seniors benefits, access to mental health resources and transitions between services, programs and providers.

As well, work has been done to relate the Health Charter to the foundational elements of patient and family centered care. These include respect and dignity, information sharing, participation and collaboration. The Health Charter also reflects the elements of the Quality Matrix developed by the HQCA: acceptability, accessibility, appropriateness, effectiveness, efficiency and safety. People have expressed concerns related to each of these dimensions and also of situations that support the important value of considering the social determinants of health. As education efforts move forward, drawing these connections will assist in creating a shared understanding of roles and expectations within the health system.

Summary of Activities

Within the first year, the Health Advocate and Seniors' Advocate assisted Albertans in resolving their concerns through existing dispute resolution processes, navigating these processes and providing education. The concerns raised by Albertans were broadly based, not unexpected in that when the OAHA opened for business, it was unknown what concerns Albertans would call about. During the first year of operations, learning to track these concerns for purposes of data collection evolved and as the OAHA's methodology improves over the next few months so will the value of the information available for reporting.

Health Advocate

From January 1, 2014 to March 31, 2015, 678 Albertans who called, emailed or came into the OAHA had files opened by the Health Advocate. Concerns were raised about the experience of Albertans whose age ranged from new born to over 90 years old and came from all geographical regions of the province including rural and urban areas.

Arising out of these files, 2,009 issues were identified which required 2,957 contacts to be made by the Advocate Representative with the client and other resources. These last numbers reflect the complexity of the issues brought to the OAHA and the required time needed to conduct research for the purposes of navigation, assistance and review.

Of the issues identified, navigating the system was a primary concern for callers. These included where to access complaint resolution processes, specific mental health and health care programs and services, financial coverage and benefit information. In response to these, we referred individuals to Alberta Health Services; various regulatory colleges; government programs such as Continuing Care, AISH and Protection of Persons in Care; primary care; and local community organizations across the province. There were also referrals to legal, financial, landlord tenant and housing resources.

In hearing Albertan's health care experiences, our staff

"Maybe stories are just data with a soul."

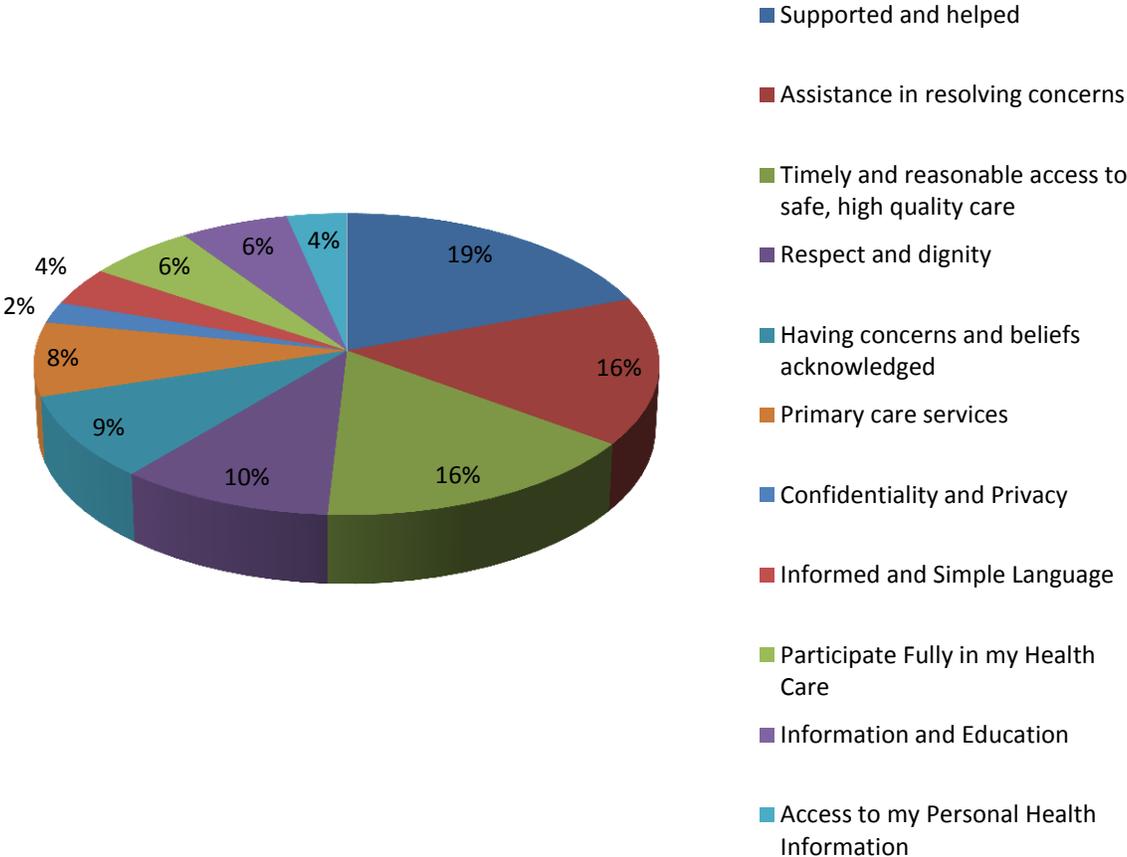
Brene Brown

Highlights

*678 Albertans served
2009 issues
2957 contacts*

identified 1,194 issues related to specific expectations set out in the Health Charter. This high number reflects that more than one aspect of the Health Charter was believed infringed in many situations. Overall, the top six concerns were about being supported and helped (18%), assistance in resolving their concerns (15%), timely and reasonable access to safe, high quality health services and care (15%), respect and dignity (10%), having their concerns and beliefs acknowledged (9%), and access to primary care services (7%). Other concerns included issues of being able to participate fully in their care, being able to understand their care plan, having their confidentiality and privacy respected, being informed in ways they understand and access to health information.

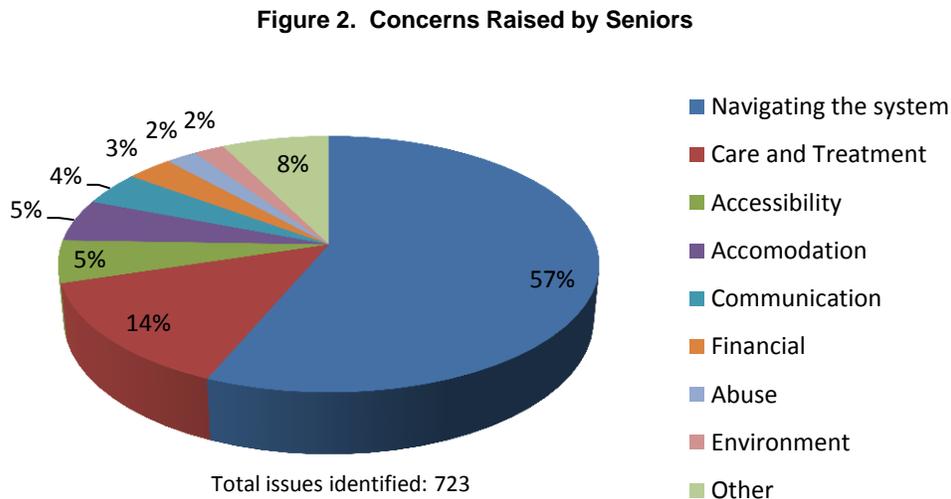
Figure 1. Health Charter Related Concerns



Seniors' Advocate

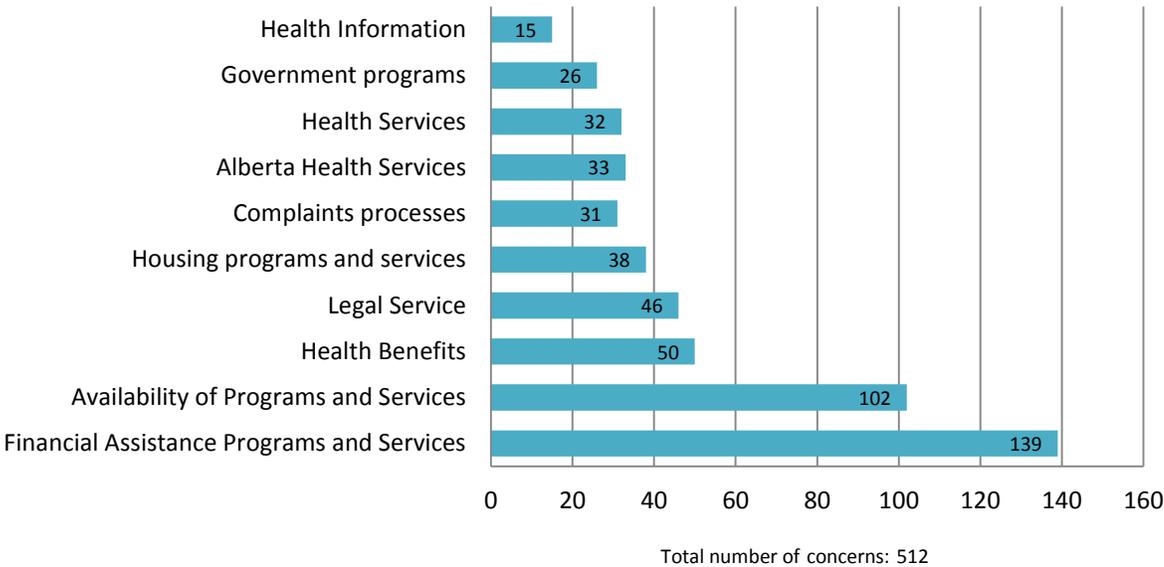
During the first year of operation, 544 Albertans contacted the Seniors' Advocate resulting in files opened. Arising out of these files, 723 issues were identified which required 1718 contacts to be made by the Advocate Representatives with the client and other resources to provide assistance and support.

The callers raised concerns about services and care and they were interested in receiving information about resources to address financial situations, housing, transportation, legal services, home care and health care. Many callers voiced specific issues around navigating the system and finding appropriate services and information. The remainder of the concerns involved care and treatment in facilities, communications challenges, accommodation, accessibility, abuse, financial issues, health care, and complaint processes in descending order.



The majority of people who contacted the Seniors Advocate expressed a concern specific to navigating the system. The Advocate Representatives heard about challenges faced by many senior Albertans and their families who were trying to find their way through multiple complex systems either to access a program or service, obtain correct information to assist in decision making or to simply get the help they need. We have heard about these challenges in such areas as: health services, physician services, hospital/clinic services, government programs and services, legal services and complaints resolution programs. The OAHA staff assisted senior Albertans and their families in 512 instances to successfully navigate these complex systems by empowering people with correct information and supporting them to become self-advocates.

Figure 3. Navigation Concerns



**Note: Other is the combined categories of the following: advocacy, accident/injury, attitude/courtesy, discharge plan, education, patient/visitor safety and responsiveness.*

Educational Services

Public education is an important part of the work of the Health and Seniors' Advocates. In the 15 months of operations, presentations were made to 54 groups and organizations and there were 93 consultations. The highlights included:

- Participation on expert panels organized by the Institute of Health Economics and the National Patient Relations Conference (Ottawa);
- Presentation for the World Health Organization Patient Engagement initiative through Canadian Patient Safety Institute which was an international
- Webinar attended by representatives of England, Oman, Jordan, Romania, Lithuania, Estonia, United Arab Emirates, Thailand and others;
- Presentation for the Canadian Patient Safety Institute Patient Safety Forum
- Presentations for a variety of other government, health care and community groups including Seniors Advisory Council of Alberta, Policy in Motion: Leadership Series, Health Quality of Alberta, Alberta Health Services Patient Family Advisory Group, National Association of Federal Retirees, Canadian Bar Association, John Dossator Health Ethics Centre;
- Featured in two digital productions, one for Alberta Health Services, Addiction and Mental Health, and one in support of Disclosure after adverse events;
- Featured as one of the leaders in health care in the *Hands in Healthcare* 2014 magazine;
- Published an article entitled "Bridging the Gaps" in the CARE magazine for the College of Licensed Practical Nurses.

Highlights

54 Presentations

94 Consultations

Strategic Relationships

The Health Advocate is a respected part of the leadership within the concerns management and quality improvement ecosystem that includes professional colleges, Alberta Health Services, the Health Quality Council of Alberta, Protection for Person's in Care office, the Office of the Public Guardian and Trustee, and the Alberta Ombudsman, Alberta Health and Alberta Seniors.

Building strong working relationships and mapping out conflict resolution pathways is key to the successful operation of the Health Advocate. The Health Advocate is participating with the following initiatives and stakeholder groups:

Health Quality Network

The Health Quality Network (HQN) is a vehicle used by organizations in Alberta who are involved in improving quality throughout the health system. The HQN brings together quality and safety stakeholders, administrators and healthcare providers and works to improve health service quality and patient safety for the citizens of Alberta through leadership, collaboration and shared learning. The Health Advocate has become a full participant in the HQN ensuring the Health Charter and the patient experience is considered.

AHS: Alberta Clinical Pathways Steering Committee (ACPSC)

The ACPSC is a strategic governing committee that will develop a provincial structure/framework for Clinical Pathways and other evidence-informed Clinical Knowledge. The Health Advocate brings the patient experience of the health journey related to continuity of care and the impact wait lists and delays have on patients and their families.

Alberta Innovates Health Solutions – Secondary Use Data Platform

The Health Advocate was invited to participate in the work to develop a proposal for an unprecedented comprehensive secondary use

data repository for Alberta. The Health Advocate brings the patient experience and concerns about health information and has offered education about the Health Charter. This work is particularly important because it will bring health and health related data together reflecting the importance of the social determinants of health, which is captured by the Health Charter and the *Alberta Health Act*.

Patient Relations Concerns Network

The Health Advocate has taken a leadership role in supporting collaboration and shared learning in the work being done to bring together the various organizations and personnel of the complaint resolution mechanisms in the Province. This is a valuable role for promoting consideration of the Health Charter in resolving complaints and concerns to ensure these processes are patient focused.

Looking Forward

Throughout the course of our first year of operations, the Health Advocate has listened to the concerns of Albertans and established relationships with other organizations involved with patient and seniors' service delivery with a focus on concerns resolution. The largest expenditure of time in many regards was working with Alberta Health, Alberta Seniors and others in the provincial government to define roles, establish budget and hire staff. In the upcoming year, attention will turn to building the office and reaching out to Albertans.

Communications and Education

The Health Advocate has responsibility for leading the implementation of the Health Charter, including education and public awareness. While outreach has been an ongoing part of activities, a concerted communications and engagement strategy needs to be developed in order to educate Albertans about the existence of the Health Charter and what it can mean for care and services in the province.

Services

There have been many Albertans who have raised concerns and requested assistance that is outside the current jurisdiction and legislated mandate of the Health Advocate and Seniors' Advocate. These requests by Albertans include the ability to intervene in finding early resolution, the ability to provide a mediation role that would help bridge multiple parts of the dispute resolution ecosystem, and to facilitate discussions with other organizations to achieve a more integrated and comprehensive resolution in complex matters. These jurisdictional queries along with the role and function of the Health Advocate and Seniors Advocate will continue to be monitored for consideration in future legislative or regulation amendment.

Restricted Access Working Group

Banning from health care facilities through the use of the *Petty Trespass Act* has been identified in the media as a concern for Albertans, particularly in regard to the importance of relationships between patients/residents in acute and continuing care and their family members. The Health Advocate is interested in reviewing the issues surrounding restrictive access. This would look at best practices and consistent guidelines for dealing with situations of conflict between families/friends and those who provide care. In some cases received by the OAHA, Health Advocate staff was able to assist in communication between the patient and/or family members and health service providers. In doing so, situations were successfully prevented from escalating to a place where restrictions might have been introduced.

Reviews

The Health Advocate has authority under the legislation to conduct reviews including own motion reviews. The Advocate also has a unique independent position within because it doesn't deliver programs and services. In the upcoming year, it's anticipated that the Advocate will look more closely, using the review function, at several issues related to the Health Charter.

Information Sharing

The three Health Advocates have similar (but not identical) functions and deal with case files that may cross Advocate jurisdiction. Information sharing is essential; however, legal concerns have been expressed about their ability to do so. While a Privacy Impact Assessment is underway, it will be important to resolve any issues around the ability to seamlessly deal with people's concerns while respecting their right to confidentiality.

Information Technology

More and more Albertans look to the internet first when searching for information and assistance. This makes a strong web presence and technological infrastructure imperative to success of the Health Advocate and its ability to assist Albertans. The Health Advocate will work to build a modern and interactive website as a key interface between the OAHA and Albertans.

Measurement

The Health Advocate will be exploring upgrading and extending the current database system to better support case management function of our work. Also, there will be a need to increase the system's ability to collect appropriate and relevant data for the purpose of measuring the impact of our work and to provide comprehensive feedback to stakeholders about the concerns being raised by Albertans about the health and seniors services systems in Alberta.

Financial Summary

	2015 Budget	2015 Actual	2014*
Salaries and Employee Benefits	\$718,000	\$497,031	
Travel and Accommodations	—	\$8,730	
Office and Administration	—	\$48,702	
General and Administrative Services	\$45,000	\$98,547	
Total	\$763,000	\$653,010	

*In 2013/2014 approximately \$96,000 were incurred for the development of the Office of the Alberta Health Advocates. The amounts are not comparable to the cost incurred in 2014/2015 and are, therefore, not included.

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