Advancing Behavioural Supports Alberta (BSA)

A Secondary Data Analysis of the November 21st, 2012 Challenging/Responsive Behaviours Symposium: Developing An Alberta Action Plan

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1. Introduction

All behaviour – whether disruptive or not – is seen as having meaning. Challenging/responsive behaviours exhibited by individuals with dementia, mental illness, addictions, brain injury, developmental disabilities and other neurological conditions (intentionally or unintentionally), are understood to be forms of communication expressed in actions, sounds, words and gestures. Such behaviours may be a reaction or response to something important to them regarding their personal, social, or physical environment, state or experience. (Adapted from MAREP's definition & philosophy of responsive behaviours[1]).

Throughout the community and continuing care sector, managing challenging/responsive behaviours in the client/resident population is an increasing concern. This challenge is being reflected in health care reports[2] [3] and industry articles[4]. In Alberta, efforts are currently underway to address the impact and disruption of these responsive behaviours or mental health and addiction issues within the continuing care continuum[5]. Some research indicates "that between 60-90% of health care residents... have at least one disturbing mental health behaviour"[6].

Having met with key stakeholders at a provincial symposium on November 21, 2012 to discuss this issue, this project – Advancing Behavioural Supports Alberta (BSA) – aims to present highlights from the symposium that have been isolated through a secondary analysis of survey and working group data regarding:

1. Clinical Best Practices (practice guidelines, competencies, evidence-based practice)
2. Education/training (existing programs, regulated/unregulated, formal training, continuing education)
3. Clinical leadership/mentoring(frontline mentoring; team resources)
4. Systems Issues/supports (policies, structures, funding, data collection)

For each of these four areas, participant feedback will be summarized regarding perspectives of current successes and challenges in managing challenging responsive behaviours, barriers/challenges to effective management, suggestions for change/potential solutions, current strategies/resources being utilized, future recommendations, and research priorities.

This analysis will aim to offer policy and decision-makers recommendations toward development of a provincial action plan around the management of challenging/responsive behaviours exhibited by the population in question.

[1] See the Responsive Behaviour Definition and Philosophy of the Murray Alzheimer Research and Education Program, University of Waterloo: http://www.marep.uwaterloo.ca/research/; internet accessed April 28, 2013.
[2] Mental Health & Drug and Alcohol Office. Aged Care - Working with People with Challenging Behaviours in Residential Aged Care Facilities. Govt. of NSW. Aug 2006.
[3] Nova Scotia. Continuing Care Strategy for Nova Scotia. 2011.
[4] Buhr GT, White HK. Difficult behaviors in long-term care patients with dementia. J AM Med Dir Assoc. 2006 Mar; 7(3);180-92.
[5] Alberta Health Services. Creating Connections: Alberta's Addiction and Mental Health Strategy. Sep 2011.
[6] MAREP. Innovations Enhancing Ability in Dementia Care. University of Waterloo. Vol 3, Issue 2, Summer 2004.

In addition to a secondary analysis of symposium data, this project will:

1. Further engage stakeholders
2. Develop a web portal and communities of practice
3. Network with local, provincial and national partners

Next steps include:

1. Secondary data analysis of working & large group discussions from the November 21st symposium
2. Preparation of a draft symposium report
3. A virtual symposium to review the report and verify recommendations
4. Formulation of a final report
5. Further BSA (Behavioural Support Alberta) website development

Estimated and Actual Project Timelines

Task	Estimated Timeline	Actual Timeline
Ethics approval	February/March, 2013	April 30, 2013
Data analysis of symposium working group discussions	January to March, 2013	May – July, 2013
Preparation of draft		August–Sept., 2013
Completion of draft written report	April 11, 2013	September, 2013
Dissemination of draft written report for review	April 12-18, 2013	September 19, 2013
Virtual symposium	April 18, 2013	
Completion of final report	May 31, 2013	October 20, 2013
Website completion		December 31, 2013

1.1 Purpose of the Report

The purpose of this report is to communicate summary findings of relevant themes and recommendations identified through a secondary analysis of the November 21, 2012 Challenging/Responsive Behaviours Symposium. The aim is to inform the development of a provincial action plan and network. The report will function as a broad level scan of system issues and potential solutions associated with the management of responsive behaviours.

1.2 Background/Context

In September, 2011, professionals affiliated with various groups, services and client populations across the lifespan began meeting around common concerns and needs of care providers in supporting individuals exhibiting challenging/responsive behaviours. Discussions focused on challenges associated with supporting this population, and strategies to better network, support caregivers, access resources, enhance caregiver competencies, and conduct research. The Challenging Behaviours Interest and Research Group (CBIRG) was formed out of the discussions, with monthly meetings commencing in November, 2011.

In 2012, numerous activities were undertaken by CBIRG and its partners: (1) CBIRG and the Institute for Continuing Care Education and Research (ICCER) successfully applied for seed funding to host a stakeholder consultation regarding the management of responsive

behaviours, (2) Norquest College successfully applied for an ACCTI grant. Jointly with the University of Alberta, research was conducted in Raymond, Alberta that examined issues faced by front line staff working with clients exhibiting responsive behaviours, offered customized staff education and training, and supported a site champion in guiding staff in the use of behavioural management strategies, (3) ICCER received funding for a Community Needs Driven Research Project. The results of the this project confirmed that the management of responsive behaviours is a key priority and need for care providers and families across the continuum of care, and (4) in November 2012, a one-day symposium was co-hosted by CBIRG and ICCER to identify and discuss issues related to the provision of health care services for individuals across Alberta, their families and caregivers, who live and cope with responsive behaviours associated with dementia, mental illness, additions, brain injury, developmental disabilities and other neurological conditions. The aim of the symposium was to explore activities occurring nationally and provincially, and to develop an Alberta action plan (involving clinical practice, education, mentorship, system issues and research) to address this challenge across the continuum of care. The establishment of Behavioural Supports Alberta (BSA) was unanimously endorsed by symposium participants.

In 2013, ICCER provided seed funding to a researcher at the University of Alberta to further the development of Behavioural Supports Alberta by (1) developing a network to support care providers in dealing appropriately with challenging or responsive behaviours, and (2) conducting a secondary analysis of data from the November 2012 symposium.

2. Secondary Data Analysis Findings

2.1 Data

This project is a secondary analysis of data collected at a symposium held on November 21st, 2012. The data analyzed included (1) the contents of presentations and group discussions which had been recorded and transcribed in order to provide summary information back to symposium organizers and participants, and (2) the results of two surveys completed by symposium participants during the symposium (data entry and analysis for these surveys was completed and presented during the symposium). All data was collected anonymously. Ethics approval for this project was granted through the University of Alberta on April 30, 2013 (see Appendix 5.1). What follows are findings of the analysis.

2.2 Secondary Analysis

A mixed methods approach was utilized in this secondary analysis to further examine information discussed and presented during the symposium. Contents of the large group discussion (1.5hr) and four working group sessions (each approx. 1hr) was examined for reoccurring themes that highlighted strategies or struggles related to challenging or responsive behaviours. Thematic analysis considered practice, organizational and system level experiences.

2.3 Participant Demographics

Participants in the symposium range from a broad range of service sectors (see Table 1) and covered many populations who may have responsive behaviours (see Table 2).

Table 1. What services sector best describes the organization that you represent/are affiliated with?

Response	Chart	Percentage	Count
Emergency or Urgent care		2%	1
Inpatient acute care		4%	2
Rehab		6%	3
Mental Health		19%	10
Home care		28%	15
Supportive/Assisted living		26%	14
Long-term/facility living		36%	19
Housing		6%	3
Other, please specify...		38%	20
		Total Responses	53

Each of the small groups discussed difficulties defining who comprises the population (i.e. what was and wasn't included/excluding as a responsive behaviour) and what was meant by the terms "challenging/ responsive behaviours" when attempting to describe the current state. This

highlights that at the time of the symposium, a clear definition of “responsive behaviours” had not been determined nor adopted.

Table 2. What populations does your organization primarily provide services to (check all that apply).

Response	Chart	Percentage	Count
Persons with developmental disabilities		38%	20
Dementia		83%	44
Delirium		40%	21
Addictions and substance abuse		28%	15
Mental health disorders		57%	30
Neurological Conditions		45%	24
Brain Injury		40%	21
Responsive Behaviours		45%	24
Other, please specify...		17%	9
		Total Responses	53

Uncertainty remained regarding the implications with defining challenging or responsive behaviours across 'diverse populations' or co-morbid populations. Additional challenges were identified when considering implications of a definition from a provider's versus a client's perspective regarding responsive behaviours.

> *"And is it from the provider's perspective or the client's perspective. Because if it's the client perspective, then something like withdrawal might be important, but if it's from the provider's it may not be that important because they've got other things to worry about. So I think the whole philosophy of client-centeredness that Ken LeClair talked about was very important." (Systems Working Group)*

Defining challenging behaviours from a staff perspective highlights current issues in how staff experience and normalize challenging behaviours.

> *"I really kind of speaking and thinking about that, the front line workers and thinking about their understanding of the definition of challenging behavior, and because if you spend some time and talking to them and they would say, I don't see this as a challenge, I don't see it as a problem. He always hit me and it's ok. It's a way that he communicates to me" (Systems Working Group)*

2.4 System Issues

Participants of the symposium were asked in a survey to identify priorites for the development and adoption of a provinicial strategy to address the management of challenging behaviours, and an integrated care system was highlighted as one of highest priorities. In working group discussions, a lack of integration across care and service sectors was specifically recognized as creating barriers to effective communication and collaboration for organizations and providers currently facing issues related to the management of responsive behaviours.

The opportunity to come together in this forum was emphasized as demonstrating the discontinuity facing organizations and service providers when considering approaches to the management of challening behaviours

> *"I think there's some good things going on, but it's sort of here and there and everywhere and there's not this way to sort of share, collaborate and bring together something. We've developed some of our own in-house training on positive behaviour supports; we look at the whole complex behavioural needs . . . we don't really have a lot of opportunities like this to sit down and share" (Education and Training Working Group)*

Symposium participants identified numerous priorities for consideration when developing a provincial strategy to address the management of challenging/responsive behaviours (see Table 3). The availability of education and training for staff, an integrated care system, caregiver support, and culturally appropriate services were most frequently noted.

Table 3. Priorities When Adopting a Provincial Strategy

Response	Chart	Percentage	Count
An integrated Care System		56%	15
Comprehensive Health services		19%	5
Collaborative care		37%	10
Culturally appropriate services		44%	12
Continuous quality improvement		41%	11
Supportive access to resources		41%	11
Supportive environments		41%	11
Caregiver support		52%	14
Education and training		59%	16
Health technology		41%	11
Other, please specify...		4%	1
	Total Responses		27

2.4.1 Health Care System Design

Symposium participants discussed several key issues regarding health care system design including:

2.4.1.1 Disconnections in delivery of services across systems

Participants questioned whether this might be addressed with a provincial framework to better support service providers in the management of challenging behaviours.

2.4.1.2 Siloed health care service structures

Participants questioned whether service issues facing populations across the health care system are reflective of siloed health care service structures and processes, rather than exclusively funding challenges.

> *"Those silos for all populations that we're here speaking of, those silos exist across addictions, mental health, and other social services . . . and those silos we can't always say, it's not just about the money. Not enough staff, not enough time [but also] the information silos too. It's not just money, it's philosophy, it's attitude, it's belief systems, it's what you truly value, and because we've done it this way all this time doesn't mean we have to keep doing it." (Systems Working Group – hereafter S WG)*

2.4.1.3 Fragmented communication across health care service structures

Communicating and exchanging information regarding behaviors reveal fragmented system experiences (across age and diagnoses) resulting in barriers facing service providers and service recipients. This points to ineffective information sharing strategies that result in poor quality and potentially misleading information about behaviours.

> *"So whether it's in the community or it's homecare or it's in hospital or back in continuing care or wherever, that is sometimes that sharing of information and that fluidness across is very fragmented, you get some stuff, you don't get some stuff or you get information and it's wrong information or it's not given and so yeah, how do we look at a common language and a common flow of information. You know like sometimes I'm a particularly, on situation where a challenging behaviour occurred, but the information wasn't shared for the community, or homecare into the facility and you know, they'll put all kinds of issues and stuff, but sometimes with behaviours there's a sometimes need to kind of sometimes keep it kind of secret" (Education and Training Working Group, hereafter E & T WG)*

2.4.1.4 Ineffective communication across systems

Information systems provide specific examples where effective communication – responsive to resource service needs related to challenging behaviours – is lacking across systems. Information needed to identify system resources is not currently responsive to changing priorities in terms of populations with increasing challenging behaviours. Specifically looking at dementia or delirium, existing data provides little clarity in terms of the extent of the resource demand in acute care, with very little additional information in primary and long term care.

> *"And I'm sure the same thing is with behaviors, as a result of dementia or delirium in acute care, there's no understanding of the, of that population in acute care. We at least have some better systems for capturing the data in continuing care; primary care same thing. We looked at physician billing data, we looked for diagnoses of delirium, very seldom as it was mentioned, because it's not the primary reason why somebody goes to their doctor, but it's that comorbidity that causes all the complex issues, or at least challenges us as service providers." (S WG)*

Information systems were also used to demonstrate fragmentation in communication across systems. Mental health does not currently use the assessment tool used in continuing care (RAI-MDS) and, although there is work underway examining how best to adapt it, the current limitations of RAI in assessing needs for individuals with mental health and challenging behaviours is agreed upon.

> *"We have mental health populations in our organization in our long-term care and the tool [RAI MDS] doesn't reflect their needs at all. We aren't using the tool yet for funding for that population. I think the system would like to, but in fact, we've been able to identify it does not reflect the needs of those populations" (S WG)*

2.4.1.5 Ineffective management of responsive behaviours

System issues were identified by symposium participants as negatively contributing to effective management of responsive behaviours, such as service transition pressures not aligning service needs with appropriate care resources and environments. The first available bed practices in continuing care, and transition pressures across service sectors, is a specific example of system issues exasperating service delivery efforts and presenting barriers for management of challenging behaviours.

> *"That first available bed and we know that literature says, especially for residents with dementia, but brain injuries as well, that more moves in the system, create more behaviours and yes, we're moving back to a system where we move them way more. So that's odd, just seems odd, we're trying to fix that problem, but we've actually created a bigger one, so..." (S WG)*

2.4.1.6 Inattention to Family Caregivers

Seniors are being forced to relocate away from family caregivers and being placed in environments that are not the most appropriate for their needs. As such transitions due to a lack of community based services do not seem to reflect the importance and value of family caregivers. More emphasis is placed on program and service delivery priorities.

> *"We need to find ways as well to be able to support our people in the community that want to be able to stay in the community a little bit longer, you know for example, the old man who still wants to do his wife's care instead of having to drive all the way to Ponoka from Red Deer while she's stuck in Alberta Hospital because she has nowhere else to be because she has Alzheimer's - which is not right. I mean this person should be able to look after their wife with a little bit of extra support from the community and unfortunately, those supports aren't always there." (Clinical Best Practices Working Group – hereafter CBP WG)*

2.4.1.7 Misalignment of service needs with resources and environments

Misaligning service needs with resources and environments was discussed as an issue for care recipients, their families, and the care service providers. Not correctly aligning service need with care providers requires a level of adaptability currently not resourced in the system.

"People need to be placed to appropriate sites, not first bed available, because first bed available is not always the most appropriate place for them to go. . . . They also don't allow a lot of credence to individual sites for their skillset, you know our system is very much first available bed. I'm talking in the long term care sector. You will do this, you will take this person and supposedly our half ways matching system, but the person on the system isn't who arrives through your door and there's no flexibility with the funding. So that's not really a strategy" (CBP WG)

2.4.1.8 Limited and inappropriate use of resources

System issues negatively contributing to the management of challenging behaviours were again brought back to a transition example in working group discussions. Transferring a senior to emergency department given a lack of capacity and resources in many continuing care environments underscores the frustration experienced with current approaches at the resident, family, care provider and system levels:

"I have a family perspective on that last point, the care centers press the panic button when they don't need to and you've got family going into ambulance and off to hospital and all they needed was some different kind of intervention, but the staff panic. They've got no resources, they've got nobody to help them resolve it; what you've got is a senior who's dehydrated and they spend ten hours in emerg for that. That's a terrible thing." (CBP WG)

2.4.1.9 Out of step with international efforts

The lack of any current policy or strategic framework in Alberta to approach the management of challenging behaviours is in contrast to current international approaches to service providers facing these same problems. Much of the symposium discussion revolved around reconciling the current system issues facing service providers in Alberta given what other provinces and countries have done to address public services and management of challenging behaviors.

"Yeah, policy and dementia policy, we have no national strategy. There's one in the UK, there's one in the US announced by the president. Most European countries, and it's not just a strategy, but they've actually devoted resources to it and are moving forward with research." (S WG)

2.4.2 Current Experiences with Information & Technology

2.4.2.1 Inconsistent Information systems

Information systems are inconsistent and do not effectively resource service needs related to challenging behaviours. Information needed to identify system resources is not currently responsive to changing priorities in terms of populations with increasing challenging behaviours. Specifically looking at dementia or delirium, existing data provide little clarity in terms of the extent of the resource demand in acute care with very limited additional information in primary and long term care.

"And I'm sure the same thing is with behaviors, as a result of dementia or delirium in acute care, there's no understanding of the, of that population in acute care. We at least

have some better systems for capturing the data in continuing care, primary care same thing. We looked at physician billing data, we looked for diagnoses of delirium, very seldom as it was mentioned because it's not the primary reason why somebody goes to their doctor but it's that comorbidity that causes all the complex issues, or at least challenges us as service providers." (S WG)

Mental health does not currently use the assessment tool used in continuing care (RAI-MDS) and although there is work to examining how best to adapt it, the current limitations of RAI in assessing needs for individuals with mental health and challenging behaviours is agreed upon.

"And the mental health group that just to go a little further, we have mental health population in our organization in our long-term care and the tool doesn't reflect their needs at all. We aren't using the tool yet, for funding for that population it would, I think the system would like to but in fact, we've been able to identify it does not reflect the needs of those popula, of all those diagnoses." (S WG)

"The frequency of the behaviours is not adequately captured in the RAI, so which translates to the workload involved from a staffing perspective, so although you can gather some information from the RAI, it's very limited and not sufficient Service level it was never intended to." (S WG)

2.4.2.2 RAI MDS

2.4.2.2.1 Effectiveness

The introduction of RAI MDS as a tool for matching people to appropriate services and continuing care environments was discussed as a negative transition away from the previous Pathways system

"I think there also has to be some anticipation of how changes are going to impact the current work. Like, you talked about Pathways earlier. Pathways was excellent because you could look at it, you could see a narrative of who you were going to get. RAI doesn't give you any of that and so yeah, like if you say, if this person shows up you have no idea who it was and so RAI was brought in without looking at what we were losing by taking away the whole pathways part so there should, there needs to be a whole analysis of what your changes are going to do." (CBP WG)

2.4.2.2.2 Limitations

RAI MDS was discussed as point in time assessment that is time consuming, not used across health care sectors, and is limited in how it captures behaviours. It was suggested that patients with responsive behaviours are being scored quite low, which may inaccurately represent funding needs.

"One of the resources that's out there, that's not used very well is we do spend a lot of time doing MDS RAI and there are behavioural [outcome] measures, indicators and you can gain data, but also you know we don't cross sectors with it, it's very sectorial. But it's available [yeah]. And in long term care, I'm not sure that the RAI instrument really

captures behaviours [it doesn't] that we're being asked to talk about here and to care for. [It's the minimum part of MDS yes] it totally is the minimum part some of the most behaviourally challenging patients scored quite low on those instruments because they're not too convincing, they're not true, there's no room for care, the doctor doesn't come and visit them and yeah they're really quite inadequate. [And that's what our funding's based on.] Exactly. "(CBP WG)

"They're a snap shot in time it's every ninety-two days [exactly] so it's not a day to day thing, we know that if a client's condition changes we're supposed to pull it out and do another week of tracking, but really it's a snap shot in time, so we can't go back." (CBP WG)

2.4.2.2.3 Translation to care at the bedside

The application of RAI MDS was discussed as requiring more effort to determine what, if any, implications there are for all of the information being collected, and if RAI MDS should or should not support care delivery at the bedside:

"We need feedback loops looking at the RAI and the MDS, you know there are all sorts of things that we can get there, but whether that's actually being brought to the bedside - that this information is there and how can we apply it to make things different. And technology, should we have equipment at the bedside to make things easier, or is that an impediment?" (CBP WG)

2.5 Education and Training

2.5.1 Elements

Participants in the Education and Training working group identified several elements necessary for education to impact clinical practice. They noted that conducting a needs assessment is essential in determining gaps which could be addressed by offering more training. Otherwise, training is not useful to staff,

"It's often easy to say education and training is a number one solution for a lot of things, but unless you really do some good needs assessments, and really clarify and really dig to get the information, you're going to do a lot of work with no results" (E& T WG)

Organizational support post-training that affords staff time to reflect, refine and practice new knowledge would facilitate successful application of newly acquires knowledge. Furthermore, participants stated that follow up by the trainer for further guidance would be helpful,

"For educators to be, to then follow up with, that group…to do an outreach following that education session and say, "So how are you putting this into practice?" or… "Do you have any questions about what you heard and what you're practicing?"(E & T WG)

Finally, the working group felt that evaluations should be conducted post training to determine if education was effective,

"*How do you know there have been knowledge transfers? So that's the question that is asked as well, "So providing this education - how did you evaluate to know that there was that transfer of knowledge?" (E & T WG)*

2.5.2 Barriers

The realities of current health care environments - including staff shortages and time pressures - often prevents front line staff from utilizing training to the fullest extent,

> *"We hear a lot, so that sounds really good, and we'd love to do that, but when they get back on the floor, reality sets in because there's, you know, three staff to however many residents, and they, they're focusing on meeting that immediate need, and they don't have the time to practice what they learned." (E & T WG)*

Due to these pressures on the front lines, certain organizations have been using technology (in the form of online modules, in-services, webinars) to deliver training. Professionals in the group who were less comfortable with technology found this to be quite challenging,

> *"I'm not that old, but our team is an older group of nurses and social workers, and this whole thing of pushing technology has been, has been kind of a bit of a barrier to learning in a way because, like, we didn't grow up with computers and IPhones and that stuff so, so everything's done on a computer now…your modules, your everything. Go on the computer and it really, it's kind of a negative…." (E & T WG)*

Therefore, although technology can be a valuable education tool, accommodations (or extra training) should be offered to less technologically experienced/comfortable individuals.

2.6 Mentoring and Leadership

Participants strongly stated that health care aides (HCAs) were essential elements of the health care team, and play a critical role in managing responsive behaviors. Managers in the focus group expressed great difficulty, however, hiring HCAs with the appropriate qualifications. A lack of standardized practice requirements across the profession results in varying levels of competency. More importantly, a great deal of discussion centered on the need for foundational skills to be taught in training programs,

> *"We need people that are trained-not off the street hiring. So we're lacking the basic foundational competencies" (Mentoring and Leadership Working Group - hereafter M & L WG).*

Another participant commented,

> *"It's no longer, I like old people or I like people with disabilities or whatever, and I like to sit and hold a hand and read this story to them and all that. This is not the job" (M & L)*

Gaps in background knowledge negatively impact the quality of care offered to patients. A manager in the group spoke of the challenge of training such staff,

"The comment that was given to her by this other [HCA} was, "we don't want to spoil the resident." I said, "if you are ever told that you are spoiling somebody, you send that person to me because that it just the wrong attitude….." (M & L WG)

It becomes the responsibility of the organization - from leadership to fellow colleagues - to upgrade and support such staff members, adding strain to an already overburdened system. Another challenge discussed by the working group revolved around literacy and English as a second language. Given that many HCAs are coming to Canada to assume these roles, this will become a bigger issue as time progresses. Some HCAs did not have the language skills to be effective in their role,

"What I've been hearing from facilities I've been in is literacy is a huge issue. So it's not just ESL, it's also literacy - for example, when you give written materials or put up posters, there's some people who don't even have the literacy to read. So they're saying we don't know how some of these people have gotten through health care aide programs…" (M & L)

2.7 Clinical Best Practices

2.7.1 Defining clinical best practice requires critical discussion

The group cautioned use of a clinical best practice approach given an evolving sense of what best practice is. They also highlighted the importance of including a patient centered approach that considers when "a best practice" may or may not be "best" for the person:

"Today's best practice is not tomorrow's best practice." (CBP WG)

"And I think we also need to put, what do the people want, what the [exactly] families want, what do our residents want. You know like we can say best practice, best practice, but it may not be a best practice for that person . . . We need to listen to what they want because ultimately, all of us are going to be in that position at some point, and I think we would all want to be listened to when we got there." (CBP WG)

Policy versus guidelines debates reflect the increased flexibility that guidelines leave to clinical judgement. However, where policies support greater accountability, they also risk acting as a barrier to clinical judgement:

"Policy is what puts you at risk, so you must do this. You may use a guideline to assist you in carrying out your policy, but a guideline can change, a guideline is based on your clinical informed evidence." (CBP WG)

2.7.2 Transitions

System design does not support patient centred care delivery. Participants noted that inappropriate transitions result due to a lack of community based services and supports that might enable family caregivers to support their loved ones. Top down program and service delivery systems tend to pay little attention to observations and experiences of family caregivers.

"We need to find ways as well to be able to support, you know, our people in the community that want to be able to stay in the community a little bit longer, you know, for example the old man who still wants to do his wife's care instead of having to drive all the way to Ponoka from Red Deer while she's stuck in Alberta Hospital because she has nowhere else to be because she has Alzheimer's - which is not right. I mean, this person should be able to look after their wife with a little bit of extra support from the community, and unfortunately, those supports aren't always there." (CBP WG)

"The structure now is top-down. Individual sites have lots of strength, but we don't tend to recognize them, so somebody might be really good at looking after chronic mentally ill people in a long-term care setting and we float a bunch of dementia patients in or vice versa even, so we're not helping them to maximize their potential. And then, the provincial policies funding, you know we get a new minister everything has to start all over again. The funding for this initiative then changes as something else is more important, so we need more consistency that way. And we have consultation teams and there's growth in that area which is all good, but still you can throw in lots of consultation teams, but if the front line staff don't know what they're doing, you know, you may as well just whistle into the wind. And then we have to take a look at the family perspective as well, I don't think there's enough of that, and nobody knows these people more than their families do. So many times their observations are discounted by the professionals."(CBP WG)

2.7.3 Physician Participation

2.7.3.1 Physician engagement and involvement

Physician engagement and involvement was identified as an important issue to address current system barriers for mental health and seniors populations. The current physician payment system was also discussed as a barrier:

"And the ones that are choosing to have education about these issues are the ones like, the converted. We're preaching to the converted, they're either the psycho junkies or the gero junkies [right]. Right, but the one's that really need it, aren't coming to anything or bailing themselves out and so it really is a difficult challenge. I think engaging physicians in this whole process too. Yeah I, I mean that could go under our research priorities too, because physicians have been excluded from the team." (CBP WG)

"And part of it is the payment system, [it is too] yeah and so we have an integrated plan that could change. So, if they're paid within the team that could [that could change] and we've seen models of them. Yes, [Swedish health care system] yeah. And parts of our system" (CBP WG)

2.7.3.2 Physician documentation re: indications for medications

Physician documentation of indicators for medication was specifically identified as an important issue for some:

> *"We're hoping that there will be more requirement of indications for medications being obvious to everybody, because so often they get ordered and nobody knows what for. We want teams that work together."(CBP WG)*

2.8 Current Strategies and Resources

A number of current strategies and resources were identified that *were working*. These included:

2.8.1 Delirium guidelines

Delirium guidelines were identified as an important current resource/strategy *(CBP WG)*. Consensus was reached that having a set of guidelines for approaching and managing delirium had made a direct impact on practice, particularly within service providers for older adults.[7]

2.8.2 Effective teams

Effective teams demonstrating clinical best practice were noted to have significant impact on care, and were easily recognized by residents and families (who readily offer positive feedback):

> *"I do think in facilities where you have a team that works, that works together that it's, you have a different outcome, so you know when you have a well-run team… you have better outcomes . . . you know residents and families will tell you immediately. You don't need to do anything, they just tell you the teams on. Yeah, they know that collection of people is there, they know. It's that competence, that competence in the group. That's for sure." (CBP WG)*

2.8.3 Tools and approaches

Tools and approaches are available to help manage responsive behaviours, although no consistent approach appears to be utilized. Participants indicated that consistency of approach would be helpful:

> *"Another positive is, there are tools available for managing [P.I.E.C.E.S] responsive behaviours, it's just they, maybe getting everybody to use the same thing would be good." (CBP WG)*

[7] See Alberta Health Service, Calgary Zone (2012). Identification & Management of Delirium in the ICU, and Mollie Cole (2011). Final Report - Promoting Early Identification and Prevention of Delirium in at Risk Older Adults through an Understanding of the Learning Needs of Individuals Who Have Personally Experienced Delirium, http://www.mentalhealthresearch.ca/KeyInitiatives/ResearchGrants/Seniors_PwD/Grants/Documents/FinalReport-IdeasFundCole.pdf

2.9 Research Priorities

2.9.1 Understanding the Issue of Challenging/Responsive Behaviours

The first research priority identified by the working groups was a basic understanding of the issue of challenging/responsive behaviours within various practice settings and communities. First, the issue requires greater examination and definition:

> *"How do we even scope the current challenges and problems, because those seem to be ill-defined and they're a context problem and measurements of course are difficult" (S WG)*

Understanding that challenging behaviours can be a large area of research, it would be helpful to systematically set research priorities either by diagnosis or setting. With numerous stakeholders at the table, perhaps beginning by setting priorities regarding issues or focus areas would be helpful.

> *"If we were just to identify a few key ones that perhaps have some strong research support behind them and actually some studies to determine which ones are actually most effective in terms of managing or helping support chronic illness. We might, we might make some headway." (E & T WG)*

After the identification of research priorities, inclusion of staff at all levels as part of knowledge translation would be essential. When engaging in research or evidence-based practice, a focus on how the knowledge can be applied is needed.

Professional staffs may be much better able to take advantage of educational opportunities, determine which is applicable to their situation/context, and experiment with different approaches. Unregulated health care providers, however, are generally less able to do so. A combination of a top down and bottom up approach is required so that the leadership team provides necessary support (e.g. whether in the form of extra staff, or adjusting tight care schedules, etc.), and staff are open and willing to learn and experiment:

> *"We hear a lot, so that sounds really good and we'd love to do that, but when they get back on the floor, reality sets in because there's, you know, three staff to however many residents, and they, they're focusing on meeting that immediate need, and they don't have the time to practice what they learned." (E & T WG)*

2.9.2 Examine the way we do needs assessment

In order to use the current data we are collecting in the facilities where challenging behaviours are taking place, the right questions need to be asked at the time of the client's needs assessment. This is important as part of collection and later research utilization to illustrate the whole picture. A research priority would be understanding if the current questions asked in the needs assessment are truly comprehensive of the client's complexity or if supplemental questions are need to inform the research analysis.

"Changing the way we do the needs assessment. You have to ask the right questions, because they tend to be the questions asked in ways that they get the answers they want. I think you have to ask the right people too." (CBP WG)

2.9.3 Application and integration of technology such as RAI MDS

Across the working groups, participants suggested that research efforts support the new implementation of technology in their setting. Technology was seen to be both a potential barrier and facilitator, and wanted reassurance that it would contribute to the care of the clients with challenging/responsive behaviours.

"General technology and barriers [yeah] using technology in the way that we [Research priority would be how we use technology?] yeah even bridging the gap between people's comfort of actually using technology. Because, I mean, if you're slow at a computer, like are you going to bring it into the client's home for a few hours and go through the assessment, right, at point of care, which is ideally what should be happening in home care, but of course practice-wise, it's not working, and we need to kind of look at why is it not working and how can we make it work better? "(CBP WG)

Additional questions were raised about the collection, use and comprehensiveness of the RAI data. As the data is collected, members of the working group questioned whether it was actually being used to support and inform research questions.

"We again queried the research that there is, what sort of evidence based, we do have the MDS and Inter-RAI now so there's a lot of data available, but the question is, are we using it. And is that a barrier? "(CBP WG)

2.9.4 Staffing: Roles and Service Delivery Models

In terms of care delivery, members of the working group wanted assurance that there was an evidence-based model of care available in their setting. Specifically within long term care, where the issue of staffing and resource allotment comes up as the barrier to client care, participants were desirous of seeing research aimed at both determining appropriate staff/resident ratios, and the way education was relayed.

"I'd like to propose a little long term care research project. I think there should be three arms to this, one's a control group for the staff for exactly the way they are, the next group is your educating the same number of staff and the third group you're doubling the amount of staff and seeing what the outcomes were behaviourally." (CBP WG)

3. Recommendations

A number of recommendations arose from the symposium including:

3.1 Establish Behavioural Supports Alberta (BSA)

Participants of the symposium unanimously supported the establishment of Behavioural Supports Alberta (BSA)

3.1.1 Defining Behavioural Supports Alberta (BSA)

Behavioural Supports Alberta would be a Community of Practice[8] and Interest[9] aimed at connecting people from across the province (caregivers, health care providers and professionals, clients, policy and decision makers, stakeholders and researchers) who are interested in and committed to working together to advance efforts related to the management of responsive behaviours exhibited by individuals from across the lifespan due to a variety of neurocognitive and mental health conditions.

> *"Could I suggest that maybe it's a coordinated, integrated system of care that addresses needs of people across the continuum irregardless of what their diagnostic background is and maybe as a person-centered form of care."*

Similar to yet distinct from Behavioural Supports Ontario, BSA would be provincial in scope, multi-system level in approach, and aligned with efforts being undertaken in Alberta (e.g. by Alberta Health Services, Alberta Health, the Government of Alberta and other partner agencies), and other national and international partners.

3.1.2 Suggested Guiding Principles/Essential Features:

Several guiding principles were identified as being priorities regarding BSA:

3.1.2.1 A Person-Centred Approach

An emphasis on the inherent dignity of people who exhibit responsive behaviours as *people who matter*, as do their families and the health care providers and caregivers who support them.

3.1.2.2 Inclusive

Inclusion of:

- People from across the lifespan with a variety of neurocognitive and mental health challenges who are receiving support across the continuum of care
- Families and other key individuals actively involved in the 'circle of care'

[8] A Community of Practice (CoP) is "a community or group of people who have made a commitment to be available to each other, offer support to share learning, and to consciously develop new knowledge. A CoP makes the intentional commitment to advance the field of practice and to share those discoveries with anyone engaged in similar work" (Wheatley, 2007).

[9] A Community of Interest (CoI) is "a group of people who share a common interest and utilize the resource centre, knowledge broker services etc. to connect and share with others on a specific topic." (Wheatley, 2007).

"Supporting families to help people live at home longer I think is really important and how to make home care so that it's responsive to the needs of the client rather than the client being responsive to the needs of the home care person."

- Front line staff

  "We have to involve the front line staff in this process too, not just do it to them; you know that's getting hard. Communication strategies are really important and then creative education strategies."
- Health care professionals – both regulated and unregulated
- Diversity among caregivers, recipients, health care providers and local contexts
- Multiple stakeholders (including government, community, family, clients, and researchers)

3.1.2.3 A Network/Community of Practice and Interest

- Facilitate communication between and within existing groups and silos
- Provide links between local, regional, provincial, and national providers (including, but not limited to, clinicians, Strategic Clinical Networks, Caregiver College, Brain Injury Association, communities of practice and interest, and researchers).
- Support efforts being made by national and provincial initiatives (e.g. the Strategic Clinical Networks - Seniors, and Addiction and Mental Health)
- Establish Communities of Practice and Communities of Interest that would be of interest to the members of BSA including those:
  - Interested in topics aligned with the symposium working group discussions:
    - Clinical best practices
    - Systems issues
    - Leadership and mentoring
    - Education and training, and
    - Research
  - Supporting persons from different diagnostic groups
  - From particular service provision groups (e.g. families, various regulated and unregulated health care providers, community members, policy and decision makers)
  - Interested in specific aspects of service provision along the care continuum

3.1.2.4 Build on the learnings of others, while maintaining a unique Alberta focus/identity

Draw on Behavioural Support Systems (BSS) and Behavioural Supports Ontario (BSO) as models, while retaining a unique accent specific to the Alberta context and needs. Consider opportunities to build capacity, ensure quality, develop leadership, facilitate change, coach, prevent injury, support self-management, enhance resiliency and adaptability, improve communication, and integrate technology as a tool.

"We don't have to reinvent the wheel and that's something I think Alberta has been famous for, so it's been good and nice to hear that we're interested in the BSO and what's been going on in Ontario and other places and not thinking that they won't work here. It isn't one size fits all and we need to really do that. We thought that policy really has to direct person-centered care - that that's not a willy nilly sort of thing that's optional, we really do need to promote that."

3.1.2.5 Access to Resources

Develop and use online media to

- Facilitate communication
- Provide access to resources, information, knowledge brokering[10] and educational opportunities
- Create a hub for connecting various communities of practice
- Increase knowledge, capacity, competency and skills through access to programs/resources

3.2 Conduct a Secondary Data Analysis

Identify and analyze Symposium themes with the aim of being a catalyst for further dialogue

[10] Knowledge brokering is the act of linking people to people or people to information in order to share learning, better understand each other's goals or professional cultures, influence each other's work, and forge new partnerships (CHSRF, 2009). Knowledge brokering helps to bridge the 'know-do' gaps and promote evidence-informed decision-making (Lomas, 2007, van Kammen et al., 2006). See "Knowledge Brokering in the Canadian Health Care System – Info Sheet." http://www.akeresourcecentre.org/files/files/KBInfoSheet.pdf

4. Next Steps

4.1 Formalize Behavioural Supports Alberta (BSA)

Further development of BSA is required including:
Description of Behavioural Supports Alberta
Establishment of Terms of Reference, Mission and Vision, Logic Model, Key Deliverables
Establishment of an Advisory Committee, Communities of Practice and Communities of Interest
Endorsement of BSA through Alberta Health Services, and/or Alberta Health
Membership

4.2 Develop a web-based presence

Development of a website for disseminating information/networking/connecting communities of practice.

4.3 Engage the Community

Provide a forum to bring together people with a passion around the management of responsive behaviours

4.4 Link with other partners

Support initiatives and collaborate with partners around common goals, for example:

- SCN Seniors Appropriate Use of Antipsychotics Project
- ICCER research
- National initiatives and collaborations

4.5 Identify research priorities and pursue opportunities.

Pursue research opportunities that support evidence based practice.
Select a few key priorities (e.g. cognitive impairments, evaluation of various intervention modalities, implications for assessment using RAI and the toolkit, ways to facilitate more effective assessment and interpretation that supports care planning).

4.6 Advocate for BSA

Advocate that BSA be:

- Resourced (have connections and liaise between already existing networks)
- Endorsed (by policy, decision-makers and various clinical associations)
- Funded (that is long-term and sustainable)
- Staffed (permanent positions that provide opportunity for growth and development of personnel and BSA)

5. Conclusion

The Challenging/Responsive Behaviours Symposium: Developing An Alberta Action Plan offered participants an opportunity to engage around and discuss both current realities and future possibilities related to the management of responsive behaviours exhibited by persons with neurocognitive and mental health conditions. Many outcomes were realized through the symposium, culminating in the establishment of Behavioral Supports Alberta.

This report, formulated from a secondary analysis of the symposium, has highlighted central emergent themes – particularly regarding 5 key areas: system issues, clinical best practices, education and training, mentoring and leadership, and research. While many challenges and barriers were noted to exist regarding the management of responsive behaviours, participants affirmed their commitment to work together locally, provincially and nationally to support those exhibiting responsive behaviours, as well as those working with them.

Given the shifting demographic toward an aging population, and the rising incidence of people with complex and chronic conditions, supports and resources that might guide interventions are essential. Work is currently underway in Alberta, across Canada and throughout the world to address this issue. Much collaboration is yet needed to enhance the current service delivery system to ensure quality care is provided to vulnerable persons. The development of BSA, fostering of Communities of Practice and Interest, and research activities into assessment, planning, interventions, and evaluation associated with responsive behaviours, have the potential to contribute to the determination of effective strategies. Further study, however, is yet required.

6. Bibliography

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Lomas, J. (2007). The in-between world of knowledge brokering. *BMJ*. 334. 129-132.

Robeson, P., Dobbins, M., DeCorby, K. (2008). Life as a Knowledge Broker in Public Health. *Journal of the Canadian Health Libraries Association*. 29(3). 79-82.

Van Kammen, J., de Savigny, D., Sewankambo, N. (2006). Using knowledge brokering to promote evidence-based policymaking: the need for support structures. *Bulletin of the World Health Organization*. 84(8). 608-612.

7. Appendices

7.1 Ethics – Notification of Approval

UNIVERSITY OF ALBERTA

RESEARCH ETHICS OFFICE

308 Campus Tower
Edmonton, AB, Canada T6G 1K8
Tel: 780.492.0459
Fax: 780.492.9429
www.reo.ualberta.ca

Notification of Approval

Date: April 30, 2013

Study ID: Pro00039343

Principal Investigator: Suzette Bremault-Phillips

Study Title: Advancing Behavioural Supports Alberta (BSA)

Approval Expiry Date: April 29, 2014

Sponsor/Funding Agency: Institute for Continuing Care Education & Research (ICCER) as represented by CapitalCare

Thank you for submitting the above study to the Research Ethics Board 2 . Your application has been reviewed and approved on behalf of the committee.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Sincerely,

Dr. Stanley Varnhagen
Chair, Research Ethics Board 2

Note: This correspondence includes an electronic signature (validation and approval via an online system).

7.2 Research Team

Organization	Name/position	Project Role	Contact Information
University of Alberta	**Suzette Brémault-Phillips** Assistant Professor	Principal Investigator	Dept. of Occupational Therapy Faculty of Rehabilitation Medicine 2-64 Corbett Hall Edmonton, AB, T6G 2G4 T: (780) 492-9503 E: suzette.bremault-phillips@ualberta.ca
Bethany Care Society	**Steven Friesen** Quality Practice Leader	Co-Investigator	1001 17 Street NW Calgary AB, T2N 2E5 T: 403-210-4685 E: friesens@bethanycare.com
Wing Kei Care Centre	**Jennifer Lee** Occupational Therapist	Co-Investigator	1212 Centre St NE Calgary, AB, T2E 2R4 T: (403) 769-3742 Ext. 2301 F: (403) 230-3857 E: jenniferlee.wingkei@gmail.com
University of Alberta	**Tamara Germani** Occupational Therapist	Research Assistant	Autism Research Centre Glenrose Rehab Hospital – E209 10239 – 111 Ave Edmonton, AB, T: 780-735-6260 E: germani@ualberta.ca

7.3 Budget

Anticipated Expenditures	Amount
Computer hardware and software to support the project (4 Nvivo licenses)	$400
Periodicals, texts and bibliographic resources	In-kind contribution
Copying, printing and postage	$200
Virtual symposium	In-kind contribution
Materials and supplies	$280
Phone	$100
Research Assistant	
» Literature Review (25hrs @ $28/hr)	$700
» Data Collection (40hrs @ $28/hr)	$1,120
» Data Analysis (75hrs @ $28/hr)	$2,100
» Report Preparation (75 hrs @$28/hr)	$2,100
Web site development	$1,000
Professional & technical services/support	In-kind contribution
Knowledge brokering	$1,000
Knowledge translation	$1,000
Space & utilities	In-kind contribution
Total	**$10,000**

7.4 Survey 1 Questions and Results

(n= 53)

1. What is the name of the organization or service area that you represent/ are affiliated with?

2. What service sector best describes the organization that you represent/are affiliated with?

- ☐ Emergency or Urgent care
- ☐ Inpatient acute care
- ☐ Rehab
- ☐ Mental Health
- ☐ Home care
- ☐ Supportive/Assisted living
- ☐ Long-term/facility living
- ☐ Housing
- ☐ Other, please specify... _____

Response	Chart	Percentage	Count
Emergency or Urgent care		2%	1
Inpatient acute care		4%	2
Rehab		6%	3
Mental Health		19%	10
Home care		28%	15
Supportive/Assisted living		26%	14
Long-term/facility living		36%	19
Housing		6%	3
Other, please specify...		38%	20
		Total Responses	53

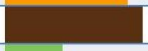
3. What age group(s) does the organization primarily provide services to?

- ☐ Child/adolescent (under 18)
- ☐ Adult (18-65)
- ☐ Senior (over 65)

Response	Chart	Percentage	Count
Child/adolescent (under 18)		13%	7
Adult (18-65)		48%	25
Senior (over 65)		85%	44
		Total Responses	52

4. What populations does your organization primarily provide services to (check all that apply)

- ☐ Persons with developmental disabilities
- ☐ Dementia
- ☐ Delirium
- ☐ Addictions and substance abuse
- ☐ Mental health disorders
- ☐ Neurological Conditions
- ☐ Brain Injury
- ☐ Responsive Behaviours
- ☐ Other, please specify... _____

Response	Chart	Percentage	Count
Persons with developmental disabilities		38%	20
Dementia		83%	44
Delirium		40%	21
Addictions and substance abuse		28%	15
Mental health disorders		57%	30
Neurological Conditions		45%	24
Brain Injury		40%	21
Responsive Behaviours		45%	24
Other, please specify...		17%	9
		Total Responses	53

5. The need for further education and support for staff training in my organization is

- ○ Low
- ○ Medium
- ○ High

Response	Chart	Percentage	Count
Low		2%	1
Medium		35%	18
High		63%	33
		Total Responses	52

6. The need for addition programs, services or supports for managing challenging behaviors in my organization

- ○ Low
- ○ Medium
- ○ High

Response	Chart	Percentage	Count
Low		4%	2
Medium		34%	17
High		62%	31
		Total Responses	50

7. The impact of challenging behaviours on the staff, clients and systems in our organization is

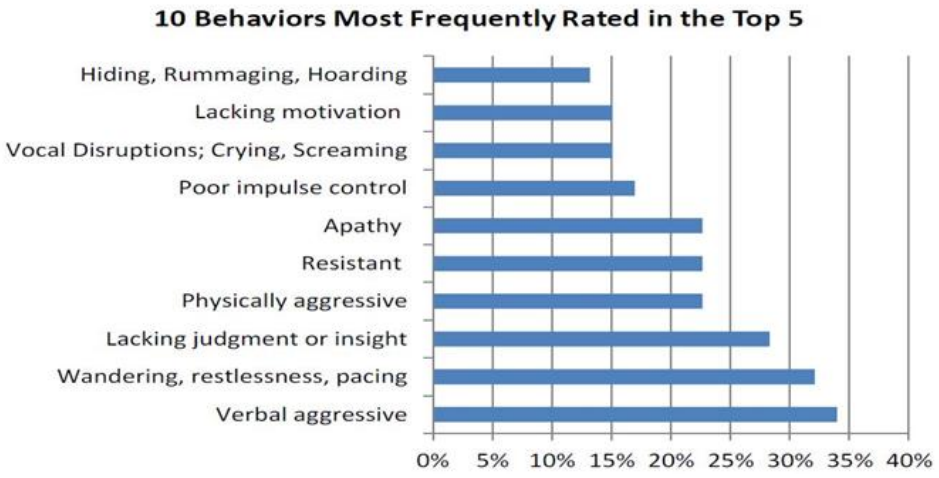
- ○ Low
- ○ Medium
- ○ High

Response	Chart	Percentage	Count
Low		6%	3
Medium		22%	11
High		72%	36
		Total Responses	50

8. For the following ranking questions: a) if you are completing this survey online, please drag up to 10 behaviors (left column) into the ranking positions (right column) you feel describes populations served by your organization; b) if you are completing this survey on paper, please rank behaviors using numbers 1-10

a) Out of the following list of behaviours, please identify and rank the 10 most common behaviours seen in populations served by your organization (with 1 being the most common of the 10 that you select)

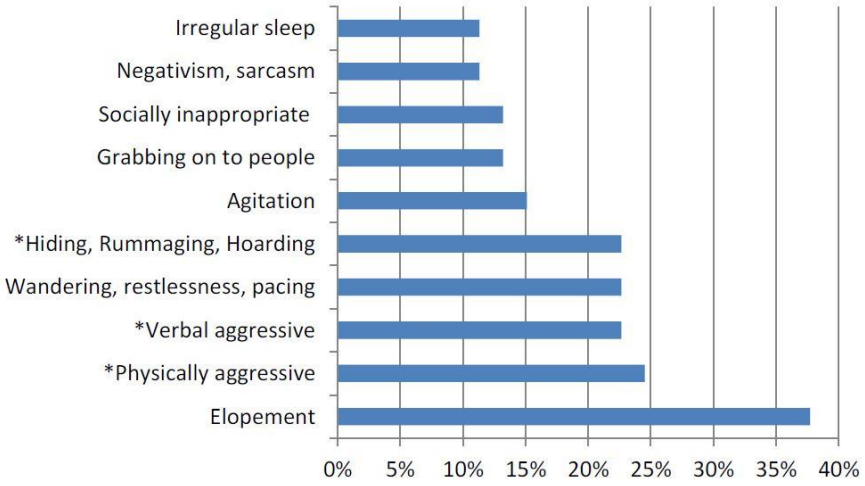
	Rank order (1 through 10 of the 10 most commonly seen behaviours in clients served by the organization, with 1 being the most common)
Elopement	
Verbal aggressive	
Physically aggressive	
Wandering, restlessness, pacing	
Negativism, sarcasm	
Grabbing on to people	
Hiding, Rummaging, Hoarding	
Sexually inappropriate	
Vocal Disruptions; Crying, Screaming	
Resistant	
Self-harming	
Irregular sleep	
Poor impulse control	
Apathy	
Inattention	
Lacking judgment or insight	
Lacking motivation	
Socially inappropriate	
Socially disengaged	
Hyper active	
Hypo active	
Impulsive	
Intolerant	
Disorganized	
Intrusive	
Agitation	
Suspicious	
Irrational	



b) Please rank the following behaviours according to how prepared (resourced, equipped) your organization is to manage them

	Rank order (Rank order 1 through 10, with 1 being the behaviours that the organization is most prepared to manage)
Elopement	
Verbal aggressive	
Physically aggressive	
Wandering, restlessness, pacing	
Negativism, sarcasm	
Grabbing on to people	
Hiding, Rummaging, Hoarding	
Sexually inappropriate	
Vocal Disruptions; Crying, Screaming	
Resistant	
Self-harming	
Irregular sleep	
Poor impulse control	
Apathy	
Inattention	
Lacking judgment or insight	
Lacking motivation	
Socially inappropriate	
Socially disengaged	
Hyper active	
Hypo active	
Impulsive	
Intolerant	
Disorganized	
Intrusive	
Agitation	
Suspicious	
Irrational	

10 Behaviors Most Frequently Rated in the Top 5



9. Please rank clinical interventions or strategies (1 through 7) that your organization most commonly uses in addressing challenging behaviors:

	Rank order (with 1 being the intervention/strategy most commonly used by the organization to manage challenging behaviours)
Medication	
Behavioural techniques, staff training	
Environmental modifications	
Group programs (exercise, recreation)	
Social interaction/ psychosocial activities	
Alternative therapies (music, pet, aroma, light)	
Therapeutic Group Activities	

	Choice 1	Choice 2	Choice 3	Choice 4	Choice 5	Choice 6	Choice 7	Total Responses
Medication	7 (20%)	3 (9%)	8 (23%)	7 (20%)	2 (6%)	1 (3%)	7 (20%)	35
Behavioural techniques, staff training	15 (43%)	7 (20%)	1 (3%)	5 (14%)	1 (3%)	4 (11%)	2 (6%)	35
Environmental modifications	4 (12%)	7 (22%)	7 (22%)	1 (3%)	7 (22%)	3 (9%)	3 (9%)	32
Group programs (exercise, recreation)	5 (16%)	4 (12%)	6 (19%)	8 (25%)	5 (16%)	4 (12%)	0 (0%)	32
Social interaction/ psychosocial activities	5 (15%)	9 (26%)	5 (15%)	5 (15%)	4 (12%)	5 (15%)	1 (3%)	34
Alternative therapies (music, pet, aroma, light)	0 (0%)	2 (7%)	4 (13%)	2 (7%)	6 (20%)	5 (17%)	11 (37%)	30
Therapeutic Group Activities	0 (0%)	4 (13%)	3 (10%)	4 (13%)	5 (17%)	8 (27%)	6 (20%)	30

10. Please identify your first and second preferences for an afternoon working group

	Choice 1	Choice 2
Clinical best practice (practice guidelines, competencies, evidence-based)	○	○
Clinical leadership (frontline mentoring; team resources)	○	○
Education/training (existing programs, regulated/unregulated, formal training, continuing education)	○	○
System issues/supports (policies, structures, funding, data collection, organization resources, strategic direction, system navigation/transition)	○	○

	Choice 1	Choice 2	Total Responses
Clinical best practice; practice guidelines, competencies, evidence-based	12 (71%)	5 (29%)	17
Clinical leadership, frontline mentoring; team resources	10 (40%)	15 (60%)	25
Education training; existing programs, regulated/unregulated, formal training, continuing educ	9 (39%)	14 (61%)	23
System issues/supports; policies, structures, funding, data collection, organization resources, strategic direction, system navigation/transition	13 (68%)	6 (32%)	19

7.5 Survey 2 Questions and Results

(Survey Completion rate: 96.55%)

Part I: Please state your level of agreement with the following statements

1. Within the organization with which I am affiliated, all behavior – whether disruptive or not – is seen as having meaning. Behaviours exhibited by clients (intentionally or unintentionally) are understood to be forms of communication expressed in actions, words and gestures. Such behaviours may be a reaction or response to something important to them regarding their personal, social, or physical environment or experience.

○ Strongly agree
○ Agree
○ Neutral
○ Disagree
○ Strongly disagree

Response	Chart	Percentage	Count
Strongly agree		48%	13
Agree		22%	6
Neutral		7%	2
Disagree		19%	5
Strongly disagree		4%	1
	Total Responses		27

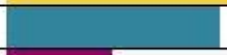
2. Within the organization with which I am affiliated, caregivers are equipped to be able to understand and effectively respond to behaviours in a client-centered manner.

- ○ Strongly agree
- ○ Agree
- ○ Neutral
- ○ Disagree
- ○ Strongly disagree

Response	Chart	Percentage	Count
Strongly agree		8%	2
Agree		36%	9
Neutral		12%	3
Disagree		44%	11
Strongly disagree		0%	0
	Total Responses		25

3. What is your organization's willingness to participate and partner in developing and implementing a behaviour support framework (Check all that apply)

- ☐ Research Support
- ☐ Knowledge Transfer/Mobilization
- ☐ Training/ Skill Building
- ☐ Advocacy
- ☐ Financial Support
- ☐ Changing Policy/Practice

Response	Chart	Percentage	Count
Research Support		56%	14
Knowledge Transfer/Mobilization		80%	20
Training/ Skill Building		88%	22
Advocacy		60%	15
Financial Support		28%	7
Changing Policy/Practice		64%	16
	Total Responses		25

4. What educational and training resources do you or your organization most commonly use to support best practice in managing challenging behaviours?

- ☐ Gentle Persuasive Approaches (GPA)
- ☐ P.I.E.C.E.S.
- ☐ U-First!
- ☐ Supportive Pathways
- ☐ Montessori Methods for DementiaTM (MMDTM)
- ☐ Sensory Modulation Approaches
- ☐ MAREP Dementia Care Education Series
- ☐ Nonviolent crisis intervention (Crisis Prevention Institute)
- ☐ Mental Health First Aide
- ☐ Effective De-Escalation Techniques (EDT)
- ☐ NICHE
- ☐ Other, please specify... _____

Response	Chart	Percentage	Count
Gentle Persuasive Approaches (GPA)		17%	4
P.I.E.C.E.S.		67%	16
U-First!		12%	3
Supportive Pathways		83%	20
Montessori Methods for DementiaTM (MMDTM)		12%	3
Sensory Modulation Approaches		8%	2
MAREP Dementia Care Education Series		8%	2
Nonviolent crisis intervention (Crisis Prevention Institute)		46%	11
Mental Health First Aide		25%	6
Effective De-Escalation Techniques (EDT)		4%	1
NICHE		8%	2
Other, please specify...		29%	7
	Total Responses		24

Other, please specify:

#	Response
1.	ASIST
2.	Alzheimer Society
3.	Eden Alternative Humanistic approaches/ experiential techniques
4.	Eden Alternative/Humanistic Approaches/ Experiential Techniques
5.	Person Centered of Care Philosophy as part of culture of change
6.	The Rosehaven Provincial Program has developed 30 + education modules in addition to PIECES related to behavior management, various diagnoses and various strategies. We deliver these face to face, through tele health and self study modules as part of our role to develop capacity for continuing care staff
7.	organization has developed 30 + face to face learning modules that are available to cont care staff- free- across the prov of AB

5. Please rank the following educational and training resources, indicating the most to least desireable of the resources (ie. those that your organization would most like to support/adopt/implement).

	Rank order (Please rank order the following 1 through 11, with 1 being the most desirable educational/training resource)
Gentle Persuasive Approaches (GPA)	
P.I.E.C.E.S.	
U-First!	
Supportive Pathways	
Montessori Methods for DementiaTM (MMDTM)	
Sensory Modulation Approaches	
MAREP Dementia Care Education Series	
Nonviolent crisis intervention (Crisis Prevention Institute)	
Mental Health First Aide	
Effective De-Escalation Techniques (EDT)	
NICHE	

	Choice 1	Choice 2	Choice 3	Choice 4	Choice 5	Choice 6	Choice 7	Choice 8	Choice 9	Choice 10	Choice 11	Total Responses
Gentle Persuasive Approaches (GPA)	2 (14)	0 (0%)	2 (14%)	2 (14)	4 (29)	2 (14%)	0 (0%)	0 (0%)	2 (14)	0 (0%)	0 (0%)	14
P.I.E.C.E.S.	8 (44)	3 (17)	0 (0%)	1 (6%)	2 (11)	1 (6%)	2 (11%)	1 (6%)	0 (0%)	0 (0%)	0 (0%)	18
U-First!	1 (7%)	3 (20)	1 (7%)	0 (0%)	1 (7%)	1 (7%)	3 (20%)	0 (0%)	1 (7%)	1 (7%)	3 (20%)	15
Supportive Pathways	4 (22)	3 (17)	4 (22%)	3 (17)	2 (11)	0 (0%)	0 (0%)	1 (6%)	1 (6%)	0 (0%)	0 (0%)	18
Montessori Methods for DementiaTM (MMDTM)	2 (14)	0 (0%)	2 (14%)	2 (14)	0 (0%)	3 (21%)	1 (7%)	1 (7%)	1 (7%)	1 (7%)	1 (7%)	14
Sensory Modulation Approaches	0 (0%)	0 (0%)	1 (7%)	3 (21)	1 (7%)	0 (0%)	0 (0%)	3 (21%)	2 (14)	3 (21%)	1 (7%)	14
MAREP Dementia Care Education Series	1 (7%)	4 (29)	1 (7%)	0 (0%)	1 (7%)	0 (0%)	0 (0%)	2 (14%)	2 (14)	2 (14%)	1 (7%)	14
Nonviolent crisis intervention (Crisis Prevention Institute)	1 (7%)	4 (29)	1 (7%)	2 (14)	1 (7%)	2 (14%)	1 (7%)	0 (0%)	1 (7%)	1 (7%)	0 (0%)	14
Mental Health First Aide	1 (8%)	2 (17)	0 (0%)	0 (0%)	1 (8%)	1 (8%)	2 (17%)	0 (0%)	2 (17)	2 (17%)	1 (8%)	12
Effective De-Escalation Techniques (EDT)	1 (8%)	1 (8%)	1 (8%)	1 (8%)	1 (8%)	1 (8%)	3 (23%)	2 (15%)	0 (0%)	0 (0%)	2 (15%)	13
NICHE	0 (0%)	0 (0%)	4 (31%)	0 (0%)	0 (0%)	2 (15%)	0 (0%)	2 (15%)	0 (0%)	2 (15%)	3 (23%)	13

Part II: Please consider the follow questions, and offer recommendations/suggestions as to how clinical best practices, clinical leadership and mentoring, education and training, and system change might best support clients and those who care for them effectively manage challenging/responsive behaviours

1. Ideally, how might clinical best practices regarding the management of challenging behaviors (including practice guidelines, competencies, evidence-based practice) be developed, implemented, supported and sustained?

#	Response
1.	A provincial group develop the guidelines and then hold sites accountable via audits and standards
2.	By communication across sectors
3.	Collaborate provincially, differentiate between regulated and non regulated staff. Key is to get leadership involved in support situations
4.	Define best practices, develop training tools (including online), get buy in from organizations for training, train staff
5.	Education of front line staff and clinicians eg: family physician
6.	Greater access to technology for front line health care providers in LTC, homecare and primary care
7.	I believe it would be good to just look at what currently exists
8.	Make it a task of clinical best practice leaders
9.	Must include frontline staff input in collaboration with mgmt/administrators, policy makers and funders
10.	Need resources for education and finance
11.	Team approaches are critical for success
12.	Through a provinicial network, sharing practices, knowledge etc. standardization
13.	Use ontario's work and revise for AB, need resources, buy in from frontline for education, framework
14.	education and support
15.	education for staff within home living to provide on-going leadership and support for management; PIECES training for specific individuals/roles in helping with clients with complex needs and exhibiting challenging behaviours
16.	management become aware of need and get vision for clinical best practice development, education, support; clinical education carry forward vision of managers
17.	one needs to involve all members of a team in all aspects of managing behaviours in some way
18.	provide info for best practices; resources; support
19.	teamwork with a variety of groups
20.	through a collaborative approach that includes front line, management, educational institutions, research group and policy makers

2. How might clinical leadership/frontline mentoring best support frontline staff in managing challenging/responsive behaviors?

#	Response
1.	Avaliability of higher staffing levels to allow for more staff training
2.	Buy in is necessary as they see the value of such an integral part of the team process
3.	Greater involvement of front line health care practitioners involved in planning strategies
4.	Have leaders with specific training (PIECES) to assist front-line staff in managing challenging/ responsive behaviours. Leaders assist in organizing case reviews/care conferences and work with interdisciplinary team by providing mentorship in managing challenging/responsive behaviors
5.	Incorporated education into new hire orientation; look at including education sessions re: behaviours into manditory ed
6.	Incorporating staff into resident specific problem solving
7.	Leadership commitment and support for any initiative in order to support change and behavior management for any front line staff (professional or unregulated)
8.	Make resources avaliable for training and ensure what is learned is reinforced by leader referring to education and application continually
9.	Mentorship/ working side by side to provide feedback
10.	Need leaders and mentors for change of behavior
11.	Provide behavior skills with challenging behaviors
12.	Ready access to debriefing and mentoring on 'just in time/ as needed basis' along with regularly scheduled topic-focused coaching, reinforcement and support
13.	Resource, education, autonomy
14.	be available; too many rules about who can help and where and when
15.	by engaging in ongoing mentoring/training sessions on-site that are responsive to frontline needs
16.	encourage, educate, support
17.	need a vision- make it a priority; need a frontline mentoring program
18.	need to have tools, should be expectations
19.	provide resources (e.g. time off for education)
20.	providing staffing levels that enable frontline staff to access education/training available to them

3. What education/training strategies (i.e. potential and existing formal and informal programs for the training of both regulated and unregulated providers) might best equip health care providers to manage challenging behaviors? Would you see the same startegies applicable in training clinical management level staff (e.g. care service mangers, shift supervisors, clinical leads)?

#	Response
1.	Best practices- online training, approaches would be different- management needs buy in first
2.	Facilitated group discussion
3.	May be helpful to have educational modules or guidelines for challenging behaviors
4.	Montissori/ Train managers first
5.	PIECES for case managers in home living supportive pathways for unregulated care providers; management to have a general presentation, training, information regarding training and impact of this work
6.	PIECES framework that works for many different diagnosis with challenging behaviours; is applicable to management level as well as to be able to support fronline staff
7.	PIECES is applicable to frontline and managers
8.	PIECES provides a framework for ongoing support for better health care providers
9.	Training needs to start at the top to be endorsed and skills demonstrated. Financial support required to ensure training avaliable to all front line staff
10.	Use of technology
11.	Using a person centered approach to care/understand the meaning of the behavior
12.	need to focus on person centered
13.	needs to be team approach with buy in from all levels/funding allocated to the initiative
14.	on-line modules; tutorials; discussion groups; auditing; targetted follow-up education and reinforcement
15.	online courses; on-site trainers/mentors; follow up mentoring/ train the trainer
16.	training at the right time (eg. provide support on site while staff face challenging behaviours)
17.	workshops- we need time away from technology since we are on our computers all day as the assessment team so face to face education preferred, with ongoing scheduled courses to look forward to
18.	yes

4. What are the key system issues, barriers or gaps in both services and supports for populations served by your organization (policies, structures, funding, data collection, organization resources, strategic direction, system navigation/transition along continuum of care, resource allocation) that limit effective management of challenging behaviours across the continuum of care?

#	Response
1.	Access to housing, medication, proverty, access to mental health, communication from and with AHS, support from AHS, building management, laundry and food service
2.	Decreased staff makes it more like that short cuts are used
3.	Environment, structure of ortanizations, historical practices, funding for training/back fill, base staffing levels
4.	Environments are restrictive, structures of oranization (redesign healthcare), policies that are historical/restrictive, funding and education/training
5.	Funding (staffing issues) and organizational resources
6.	Human resources/man power
7.	Lack of resources for management of behaviors of long term care patients
8.	Limited resources, organizational understanding and commitment
9.	Management attitudes and acceptance of change, put person at centre of practice
10.	Need change management, and buy in from all team members
11.	Ongoing training, sustainability, environmental challenges, staffing
12.	funding
13.	funding for adequate staff levels to maintain quality care and resources for staff to access ongoing training
14.	funding; limited resources for staffing; staff not able to apply what they have learned due to lack of support from leadership
15.	ineffective partnerships with primary care/ acute care; lack of regular surveillance prevention and health and wellness promotion
16.	key barriers are funding for staff replacement to attend educ sessions; lack of management support/ emphasizing the importance of staff edu; employee engagement
17.	lack of education and training; too many priorities within home living limited resources related to providing this education and training
18.	lack of experts in system (e.g. # of senior nurses retired with intro of new technologies); push for 'quick' assessments to get clients onto waitlist so no time for proper evaluation and tx before for placement; waitlist to see specialists/consultants to find solutions in a timely manner
19.	lack of understanding as to exactly what to support; facing staffing issues
20.	management unwilling to put up funding for continous educational support for staff
21.	stovepipe funding systems and lack of ability to move funds between sectors; even within streams of cont care at one site

5. What might assist in overcoming system issues/barriers so as to effectively support the management of challenging/responsive behaviours along the continuum of care?

#	Response
1.	Buy in from zone decision makers, clearly defined expectations from a provincial perspectives, enhanced communcation between AHS/care partners
2.	Collaborative/integrated care system committed to person directed/family (people strategy)/ Invert pyramid structure of care-acute care not foremost, continuing care on top
3.	Establish priorities of person not system/focus on outcome for person not monetary or other
4.	Funding, education needs to be ongoing, education integrated into professional education
5.	Integrated primary health care programs and initiatives
6.	More support staff for therapeutic activities/more care staff
7.	Resource allocation to appropriate training and then follow up support and mentoring
8.	Shortage of front line care givers-recruitment/government support in international labor market
9.	Support to staff and education/physician buy in
10.	Using similar technology and approaches across the system to enhance communication
11.	commitment from minister level to policy change that translates into a person centred approach in developing funding models for effective seniors care
12.	educate management and staff
13.	establishment of a common goal and purpose; reduction/elimination of competition for funding/resources
14.	everyone working together
15.	if this strategy aligns to destination home it can be made a priority
16.	management buy in; staff to see the importance; senior admin to support ongoing education
17.	more collaboration/ communication between professionals such as this symposium to raise issues and form solutions to issues; education for front line and managment; empower groups such as mental health to create living options for the challenging population- presently they rely on supportive living options
18.	provide clear road map and algorythim to deal with challenging behaviours

Part III: The following questions relate to the development of an Alberta Action Plan. Please respond to the following questions and offer any additional thoughts that might reflect aspects/key components of any potential plan:

1. Do you feel Alberta would benefit from a provincial framework/strategy to address the management of challenging/responsive behaviours along the continuum of care?

- ○ Yes
- ○ No

Response	Chart	Percentage	Count
Yes		100%	27
No		0%	0
	Total Responses		27

2. If yes, which of the following features would you see as being integral to the framework:

- ☐ An integrated Care System
- ☐ Comprehensive Health services
- ☐ Collaborative care
- ☐ Culturally appropriate services
- ☐ Continuous quality improvement
- ☐ Supportive access to resources
- ☐ Supportive environments
- ☐ Caregiver support
- ☐ Education and training
- ☐ Health technology
- ☐ Other, please specify... _____

Response	Chart	Percentage	Count
An integrated Care System		77%	20
Comprehensive Health services		38%	10
Collaborative care		54%	14
Culturally appropriate services		65%	17
Continuous quality improvement		69%	18
Supportive access to resources		58%	15
Supportive environments		77%	20
Caregiver support		69%	18
Education and training		88%	23
Health technology		46%	12
Other, please specify...		8%	2
	Total Responses		26

Other, please specify:

#	Response
1.	Person and family centered
2.	need to go beyond the health system

3. If a provincial strategy was to be adopted, which of the following guiding principles would you like to see incorporated:

- ☐ Care is relationship-centred and person-directed
- ☐ Care system must be accountable and provide leadership
- ☐ Behaviour is communication
- ☐ Care is provided in the least restrictive environment
- ☐ Respect is given for all
- ☐ Care includes health promotion and chronic disease prevention
- ☐ Other, please specify... _____

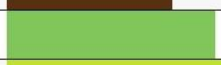
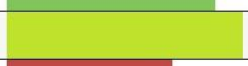
Response	Chart	Percentage	Count
Care is relationship-centred and person-directed		96%	26
Care system must be accountable and provide leadership		56%	15
Behaviour is communication		74%	20
Care is provided in the least restrictive environment		63%	17
Respect is given for all		85%	23
Care includes health promotion and chronic disease prevention		48%	13
Other, please specify...		11%	3
	Total Responses		27

Other, please specify:

#	Response
1.	Better physical and social environments
2.	Supportive care to support informal caregivers in the home
3.	provide care to the client with a family focus

4. If a provincial strategy was to be adopted, which of the following components would you like to see prioritized:

- ☐ An integrated Care System
- ☐ Comprehensive Health services
- ☐ Collaborative care
- ☐ Culturally appropriate services
- ☐ Continuous quality improvement
- ☐ Supportive access to resources
- ☐ Supportive environments
- ☐ Caregiver support
- ☐ Education and training
- ☐ Health technology
- ☐ Other, please specify... _____

Response	Chart	Percentage	Count
An integrated Care System		56%	15
Comprehensive Health services		19%	5
Collaborative care		37%	10
Culturally appropriate services		44%	12
Continuous quality improvement		41%	11
Supportive access to resources		41%	11
Supportive environments		41%	11
Caregiver support		52%	14
Education and training		59%	16
Health technology		41%	11
Other, please specify...		4%	1
	Total Responses		27

Other, please specify:

#	Response
1.	see number 2

5. Which of the following Core Competencies do you feel immediately need additional supports for health care providers working with this population:

- ☐ Knowledge
- ☐ Cultural Values and Diversity
- ☐ Person Centred Care Delivery
- ☐ Prevention and Self-Management
- ☐ Clinical Skills
- ☐ Resiliency and Adaptability
- ☐ Field Based Quality Improvement and Knowledge Transfer
- ☐ Collaboration and Communication
- ☐ Change Management Skills
- ☐ Technology Skills
- ☐ Leadership, Facilitation, Coaching and Mentoring
- ☐ Professional and Work Ethics
- ☐ Other, please specify... _____

Response	Chart	Percentage	Count
Knowledge		56%	15
Cultural Values and Diversity		41%	11
Person Centred Care Delivery		78%	21
Prevention and Self-Management		41%	11
Clinical Skills		33%	9
Resiliency and Adaptability		30%	8
Field Based Quality Improvement and Knowledge Transfer		33%	9
Collaboration and Communication		41%	11
Change Management Skills		48%	13
Technology Skills		15%	4
Leadership, Facilitation, Coaching and Mentoring		85%	23
Professional and Work Ethics		15%	4
	Total Responses		27

Additional Comments:

1. We can train/educate staff but this knowledge improvement is of little value when there are no caregivers avaliable to deal with behaviors (eg: staff are providing care to other residents, no one left to oversee the other patients' activities) and more staff would go a long way to preventing these behaviors

7.6 Symposium Working Group Session

Participants were invited to participate in working groups focused on 4 different themes:

1. Clinical Best Practices (practice guidelines, competencies, evidence-based practice)
2. Clinical leadership/mentoring (frontline mentoring; team resources)
3. Systems Issues/Supports (policies, structures, funding, data collection)
4. Education/training (existing programs, regulated/unregulated, formal training, continuing education)

In each of the 4 working groups, participants were asked to discuss the following and capture key ideas under each heading and bring these back to the large group for discussion:

- Current experiences (successes and challenges in managing challenging responsive behaviours)
- Current barriers/challenges along with accompanying suggestions for change/potential solutions
- Current strategies/resources
- Recommendations
- Research priorities

7.7 Focus of Large Group Discussion

As a large group, the following key issues were discussed:

1. Desired provincial future state in addressing challenging /altered behaviours along the continuum of care
2. Go forward mechanisms for:
    - Health care services
    - System change
    - Policy
    - Education/training
    - Informing of a research agenda