

AGAC Conference 2019

Supported Decision Making for Health Care and Financial Management: Research from British Columbia, Canada

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Outline

- Putting BC into Context: Range of decision making laws in Canada
 - Other models in Canada
 - Non court: Yukon and Alberta
 - Court: Alberta, Saskatchewan and Quebec
- British Columbia's "Section 7 Representation Agreement"
 - Legislative Framework
- The BC experience since February 2000
 - Implementation issues and challenges
 - CCEL recent/current research

The laws and terminology for decision-making frameworks and safeguards in Canada and the status of supported decision-making is as varied as the country itself:

- 9 common law provinces
- 1 civil law province (Que)
- 3 territories. (Yukon, NWT and Nunavut)



Decision-making options in Canada

- Advance planning documents, court ordered, defaults
 - Powers of attorney/Proxy – appoint substitute (financial/personal & health)
 - Effective immediately or upon an event/incapacity
 - Guardianship – court appoints substitutes (financial, personal, health)
 - Statutory guardianship – non court process – PGT is financial guardian
 - Defaults – health care decisions (select substitute from a list)
 - Advance directives (health care consent/refusal of treatment)
- Co- and assisted decision-making court orders (3 jurisdictions)
- Supported decision-maker documents (3 jurisdictions)
 - Issues and concerns about risk and undue influence

Supported, co- and assisted decision making in Canada

- Alberta:
 - Co-decision making court order for personal & health care
 - Supported decision-making authorization signed by adult for personal & health
- Saskatchewan:
 - Property or personal co-decision maker court order
 - Temporary property or personal guardian
- Nova Scotia:
 - Representation orders
- Quebec
 - Court ordered adviser to assist with administration of property
- Research? When used? Experiences? Challenges?

Supported, co- and assisted decision making in Canada

- British Columbia
 - Supported decision making recognized through Representation Agreements
 - All decision making legislation now require representatives, attorneys, guardians and temporary healthcare decision makers to encourage the adult's involvement in decision-making [note: expressed differently]
- Yukon
 - Associate decision-maker (supported decision-making agreement)
 - Gives supporters legal status to be with adult and participate in discussions; help communicate decisions; undue influence prohibited
 - Representative (representation agreement)- financial or personal – limited range of daily living decisions – substituted decisions.
- Law Commission of Ontario (2017) – further study

A closer look at BC's Representation Agreement

- Purpose of the Act (s.2) is to provide a mechanism:
 - a) to allow adults to arrange in advance how, when and by whom, [decisions] will be made if they become incapable of making decisions independently, and
 - b) to avoid the need for the court to appoint someone to help adults make decisions, or someone to make decisions for adults, when they are incapable of making decisions independently
- Presumption of capacity (s.3)
 - (1) Until the contrary is demonstrated, every adult is presumed to be capable of making, changing or revoking a representation agreement, and making decisions about personal care, health care and legal matters and about the routine management of the adult's financial affairs.
 - (2) An adult's way of communicating with others is not grounds for deciding that he or she is incapable of understanding anything referred to in subsection (1).

BC's Representation Agreement – 2 Kinds

- Section 7 – Standard Provision Agreement: An adult may authorize his or her representative to help the adult make decisions, or to make decisions on behalf of the adult, about any or all of the following:
 - the adult's personal care; [see limits]
 - routine management of the adult's financial affairs [see limits]
 - major health care and minor health care, [see limits]
 - obtaining legal services for the adult and instructing counsel to commence proceedings, except divorce proceedings, or to continue, compromise, defend or settle any legal proceedings on the adult's behalf.
- Section 9 – Non-Standard agreements – Health and Personal Care only
 - Companion to enduring power of attorney for financial matters

Test of Incapability to make s. 7 and s. 9 agreements

- An adult can make s. 7 agreement even if incapable of:
 - making a contract, managing his or her health care, personal care or legal matters, or the routine management of his or her financial affairs.
- When determining if capable of making an agreement, consider all relevant factors. Examples include whether the adult:
 - communicates a desire to have a representative make, help make, or stop making decisions;
 - demonstrates choices & preferences & can express feelings of approval or disapproval of others;
 - is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult;
 - as a relationship with the representative that is characterized by trust.

Representative's Powers

- Retain services of a qualified person to assist the representative in doing anything the adult has authorized the representative to do. (s. 17)
- Request information and records respecting the adult for whom the representative is acting, if the information or records relate to (s. 18(1))
 - the incapability of the adult, or
 - an area of authority granted to the representative.
- Same right to information and records described as the adult (s. 18(2))

Representatives Duties

- Duties include (s. 16):
 - Act honestly and in good faith
 - Determine adult's wishes
 - otherwise pre-expressed wishes, then values and beliefs, then best interests
 - Accounting
 - No delegation except investment decisions
 - Not to disclose personal information unless required (s.22)
- Provisions to report concerns about making of RA, decisions being made, failure to comply with duties

Safeguards

- Prohibited persons
 - Provide personal care or health care services or employee in facility that does
- PGT may act
- Trust company may act if not for personal or health care
- Must have a monitor if RA is for financial decisions unless have 2 representatives or representative is the spouse/PGT/Trust company
- Two witnesses unless a lawyer or BC notary public
- Representative(s) must sign a certificate
- Witnesses must sign a certificate

Monitors – Duties and Powers (s.20)

- Make reasonable efforts to determine if representative is complying with duties
- At any reasonable time, may visit and speak with the adult
- Anyone having custody or control of the adult must not hinder the monitor from visiting or speaking with adult.
- If has reason to believe that a representative is not complying with duties:
 - (a) may require the representative to (i) produce accounts and other records required to be kept under this Act, and (ii) report to the monitor on the matters specified by the monitor, and
 - (b) must notify adult, representative and all other representatives, including alternates, of the monitor's reason for the belief
- If still has reason to believe the representative is not complying with duties, must promptly inform the Public Guardian and Trustee.

CCEL: *Conversations About Care (Feb 2019)*

- Examines health care consent for people with dementia living in facilities
- Methodology:
 - 65 key informant interviews
 - 13 focus groups (14 people living with dementia; 44 family caregivers)
 - 8 conferences and community presentations – identified concerns of HCPs
 - Online survey of family caregivers (28 respondents)
 - Research
 - Policy recommendations developed with advisory committee
- Findings:
 - Importance of both formal and informal supported decision-making
 - Lack of education and understanding of both health care consent laws and supported decision making generally (for professionals, patients and families)

CCEL: *Conversations About Care (Feb 2019)*

- 34 recommendations to improve compliance with health care consent laws including recommendations related to supported decision making:
 - Education:
 - Develop comprehensive public education plan regarding supported and substitute decision making for health care and provide funding to non-profits to further engage in this work (R#34) Includes professionals
 - Legislation, including:
 - Make duty to engage adult consistent across decision making legislation
 - Enhance legislative provisions to reflect principles of supported decision making
 - Providing supports (e.g. interpretation services (R#29))

CCEL: Inclusive Investing – Respecting the Rights of Vulnerable Investors through Supported Decision Making

- **Research question:** How can Canadian investment advisors, adults with cognitive and decision-making challenges, and supporters incorporate supported decision making into the investment decision-making process while guarding against undue influence and financial abuse?
 - How are vulnerable investors using supported decision making today?
 - How can supported decision making during the investment process be facilitated to maximize an investor's access to investment options while minimizing the loss of autonomy?
- **Consultation:** key informant interviews (40 & counting); focus groups(3-6) with people with lived experience (up to 10 at each); round tables (2) (16-24 participants at each)
- Research, analysis and writing to follow – target release early 2020

Inclusive Investing: Early observations (BC & Ont)

- Informal support is common and often not considered supported DM
- Wide range of scenarios and circumstances – from level of cognitive limitations to type of investments and value
 - From no decision making experienter to losing a lifetime of decision making autonomy
- Limited use of s 7 RA in BC
- Interest in investment sector: cognitive issues are increasing concern
 - Need support, tools, education
 - Need regulatory guidance and possibly legislative support
- Wide range of strategies are used that leverage range of skills (e.g):
 - Personal relationships between client & supporter and/or investment advisor
 - Legal training (e.g. client interviews for capacity, understanding, undue influence)

BC's Experience with s. 7 RA - Issues

- Limited research and data – in addition to CCEL:
 - Nidus: 2006-2009 data for 989 s.7 RAs: http://www.nidus.ca/?page_id=234
 - who is making s.7RA? who is appointed as rep and monitor?
 - M Browning: PHD –
 - Study of 7 individuals with intellectual disabilities with RA or microboards
 - Feb 2018: *Developing an Understanding of Supported Decision-Making Practice in Canada: The Experiences of People with Intellectual Disabilities and Their Supporters*
- Lack of awareness & understanding of supported decision making generally
- Distinction between substitute & supported decision-making poorly understood
- Concerns about risk of undue influence and abuse
- 3rd party liability
- S. 8 test of incapability untested in court (19 years later!)

BC's Experience with s. 7 RA - Challenges

- Legal profession:
 - If adult cannot contract, then adult cannot hire lawyer to prepare s. 7 RA
 - Law Society guidance could be strengthened
 - 2013 BCLI recommended amending RAA: “a person capable of making RA has capacity to retain lawyer to advise on & draft a RA”
 - Recommended again in Feb 2019 report – *Conversations about Care (R#32)*
- Paradigm shift for public, professionals and third party service providers
- Some cynicism as to what adult's really understand

BC's Experience with s. 7 RA – Challenges cont'd

- How to assess adult's understanding
- Developing skills of supporters
- “opening eyes” to possibilities
- Systemic challenges
 - Third parties need time and support to engage with supported decision making process
 - Physicians need to be paid for time required
- Tools and resources for adults, supporters, professionals and service providers
 - See Nidus “feature stories” for high level examples

Opportunities in BC

- Financial Abuse:
 - PGT recognizes as a way to avoid statutory or court guardianship where trusted relationships exist
- PGT seeking ways to foster participation of adults in decisions
 - <http://www.trustee.bc.ca/Documents/PCS/Fact%20Sheet%20-%20Fostering%20Independence%20and%20Decision%20Making.pdf>
- Learn from families and support groups
- Leverage goodwill of third parties, including financial institutions
- Leverage investment sector interest in recognizing quality of decision making in clients with mental health or life stresses



THANK YOU

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