

October 20, 2021

# Inclusive Decision Making with the Dementia & Disability Community

Jessica Fehrenbacher, Myrna Norman, Jerry Gosling





Jess  
Fehrenbacher



Myrna  
Norman



Jerry  
Gosling

# About the CCEL

Our work =

- Law reform
- Consultation
- Research
- Legal education



CANADIAN CENTRE FOR  
**ELDER LAW**

# Current CCEL areas of research:

Elder abuse and  
neglect — law and  
policy across  
Canada

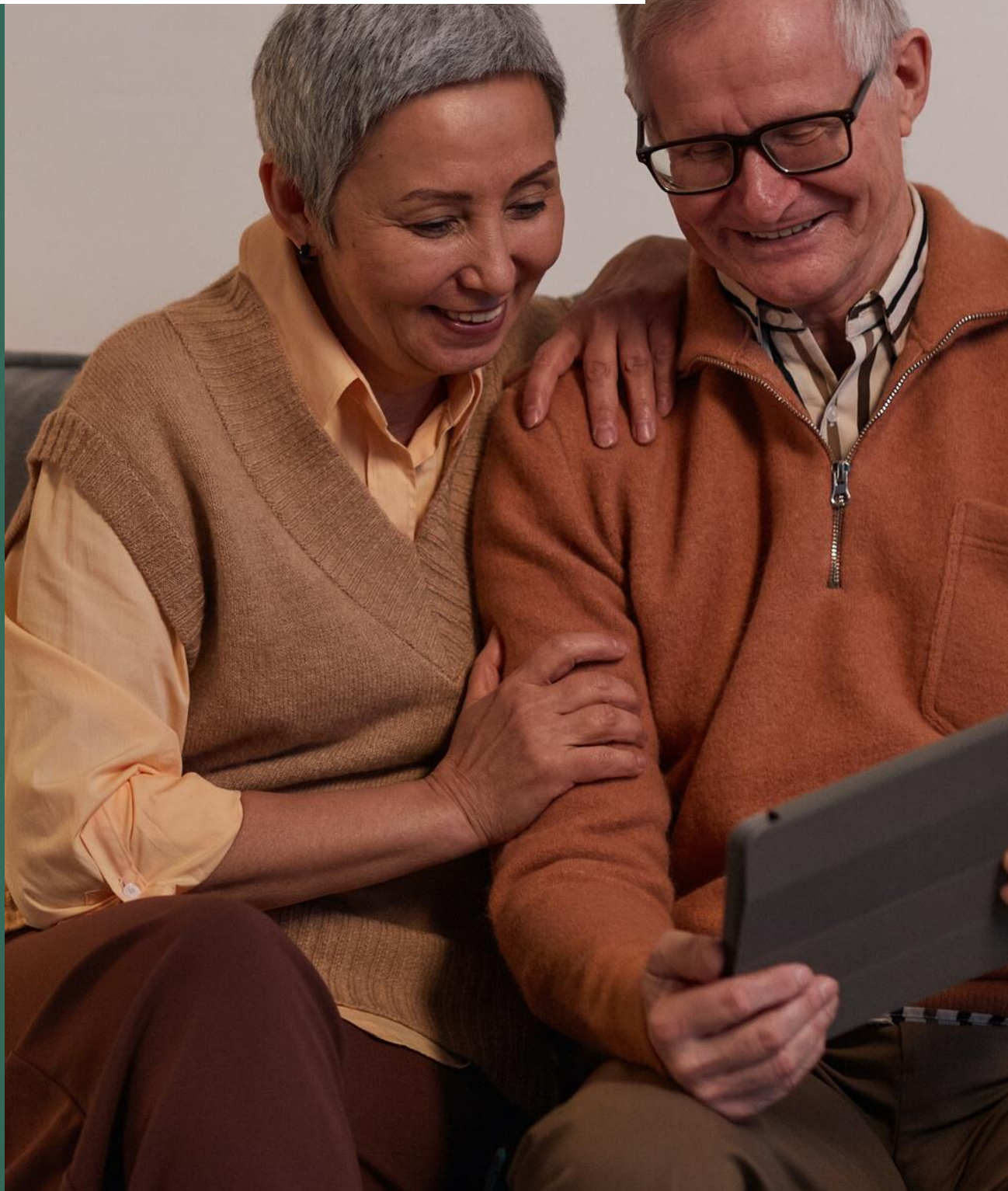
Unregulated health  
care assistants —  
legal models for  
practice oversight

Consent to participate  
in research — laws and  
ethics for inclusion of  
people living with  
dementia

Decision-making,  
mental capacity,  
and disability



# Engaging People Living with Dementia in Decision-Making



## PROJECT GOAL

To change how health and personal care decision-making is approached so that people living with dementia will be supported to participate meaningfully in all the everyday decision-making that matters to them, to the best of their abilities.



# Project Objectives

- Consult with people with different kinds of disabilities to identify strategies that support people living with dementia to be meaningfully involved in decision-making
- Create resources for teaching healthcare stakeholders how to support people living with dementia to participate as much as possible in decisions that impact their lives.

# Project Partners



# About dementia

- The likelihood of dementia increases with age
  - 1% of those under 65 years of age
  - 2.5% of those between 65 and 74
  - 30-40% of those over 85 years of age
- 1 in 11 Canadians over the age of 65 (approx. 500,000 people) has Alzheimer's or a related dementia
  - Is not a part of normal aging

## **Definition:**

- Changes in thinking, feeling, behaving and remembering severe enough to interfere with the ability to function independently
- Develops slowly and progresses irreversibly over time



# Legal Framework

BC Adult Guardianship Act

BC Representation Agreement Act

BC Health Care Consent and Care Facility Admission Act

BC Patients Property Act

BC Residential Care Regulation

Canadian Charter of Rights and Freedoms

BC Human Rights Code

United Nations, Convention on the Rights of Persons with Disabilities

# UN Convention



Disabled people have the same right to make their own decisions about important things as everyone else.



Disabled people should have the proper support they need when making decisions.



If a person really does need someone to speak for them there should be rules to make sure this is done properly.





# Summary of the Law in BC

- All adults are presumed capable of decision-making—regardless of age or disability
- People with disabilities have a right to accommodation of their communication needs and abilities
- The right to make any decision depends on whether a person is able to understand information relevant to that specific decision
- The role of supportive decision-makers is protected
- Substitute decision-makers have a duty to consult with the people they represent

# The Challenge

In spite of robust legal rights, people living with dementia are often excluded from decision-making due to:

**Ableist and ageist attitudes regarding decision-making capacity**

**Lack of health care staff knowledge of legal rights and duties**

**Poor understanding of dementia and its impact on capacity**

**Health institution emphasis on patient outcome over process**

**Staffing issues and institutional capacity**

**Barriers faced by unique populations—racism, health literacy, colonization, lack of cultural safety and humility, and more**



# Key methods

- Leadership by a Dementia Advisory Council
- Consultation with diverse disability populations
- Health care sector consultation including family caregivers
- Tools grounded in the experiences of people living with dementia
- Expertise of an Indigenous Facilitator





Story of  
lived  
experience:  
**Myrna**



# Community Consultations

**16** people living with dementia

**21** people living with disabilities

**37** family care partners

**12** English language group consults

**1** Punjabi-language group consults

**6** individual interviews

# Decisions that matter

- ALL decisions
- Health care decisions
- Future and financial decisions
- Everyday decisions
- Living arrangements and personal care
- And more.

“I would really want to be **not just a rubber stamp**, but deeply engrossed [in decisions]... with the help of my partner.”

*- Person living with dementia*

“Decisions that affect me directly, I want to be in charge of.

*- Person living with a disability*

# Barriers to inclusion

- Navigating the system
- Limiting policies / laws
- Lack of support options
- Stigma & assumptions
- Language, communication, & cultural barriers

“Stereotypes hinder a lot of people in their decision making, because they read the diagnosis or whatever on a piece of paper and **automatically assume** something about that person.”

*- Person living with autism*

# Limitations of others

“[My friend] always went to my doctor’s with me, and the two of them talked together **as if I wasn’t even there...** so I got to the point where I wouldn’t take her anymore and he had to talk directly to me.”

*- Person living with dementia*

- Other people taking over
- Not having people you trust
- Attitudes of others



# Limitations of self

- Cognitive limitations
- Doubt
- Emotions

“My own self [prevents me from making decisions]. Basically, I have a hard time when I want to go do something, and all the sudden some part of my brain tell me, No, this isn't something that you can do, and I usually back off before even trying. And that's a big thing for me.”

*- Person living with a disability*

# It's complicated

“Sometimes, what was in my best interest was not always [in] hers. I was her agent in effect working [on] her behalf. And I had to factor that in all the decisions that were made.”

- *Care partner*

- Which decisions to let go of?
- Lack of clarity
- Messy relationships
- Personalities
- In whose best interest?
- Dementia progression and decision making

# Individual strategies

- Communication
- Recording
- Advance decisions
- Enough time
- Visuals
- Clarifying questions
- Positive self talk
- Self-advocacy
- Prioritizing
- Involving others

“I like to think about, well, who can I talk to about this issue about this decision, but I really do give a lot of thought as to who to talk about it with.”

- *Person living with a disability*

# Relationships & Boundaries

- Asking others for help & reminders
- Consulting with person you trust
- Entrusting others with decisions
- Boundaries in control over decisions

“I have a daughter who wants to control everything. So I have to tell her, manage the investments. You are the beneficiaries of this. I will not even think about what you will decide... but my house, I will take care of my house... Just focus on the things I am giving you... I have to be so careful about that, because some people can be so pressing.”

*- Person living with MCI*

# Care partner strategies

“One of the things I also recognize is if I don’t prompt these discussions, she won’t bring it up... As long as there’s some level of interchange then you can continue doing it.”

- *Care partner*

- Advocate & translator
- Simplifying options
- Prioritizing input
- Enough time
- Emotional level
- Visuals
- Reframing
- Compassionate fibbing
- Third person



# Implications for practice

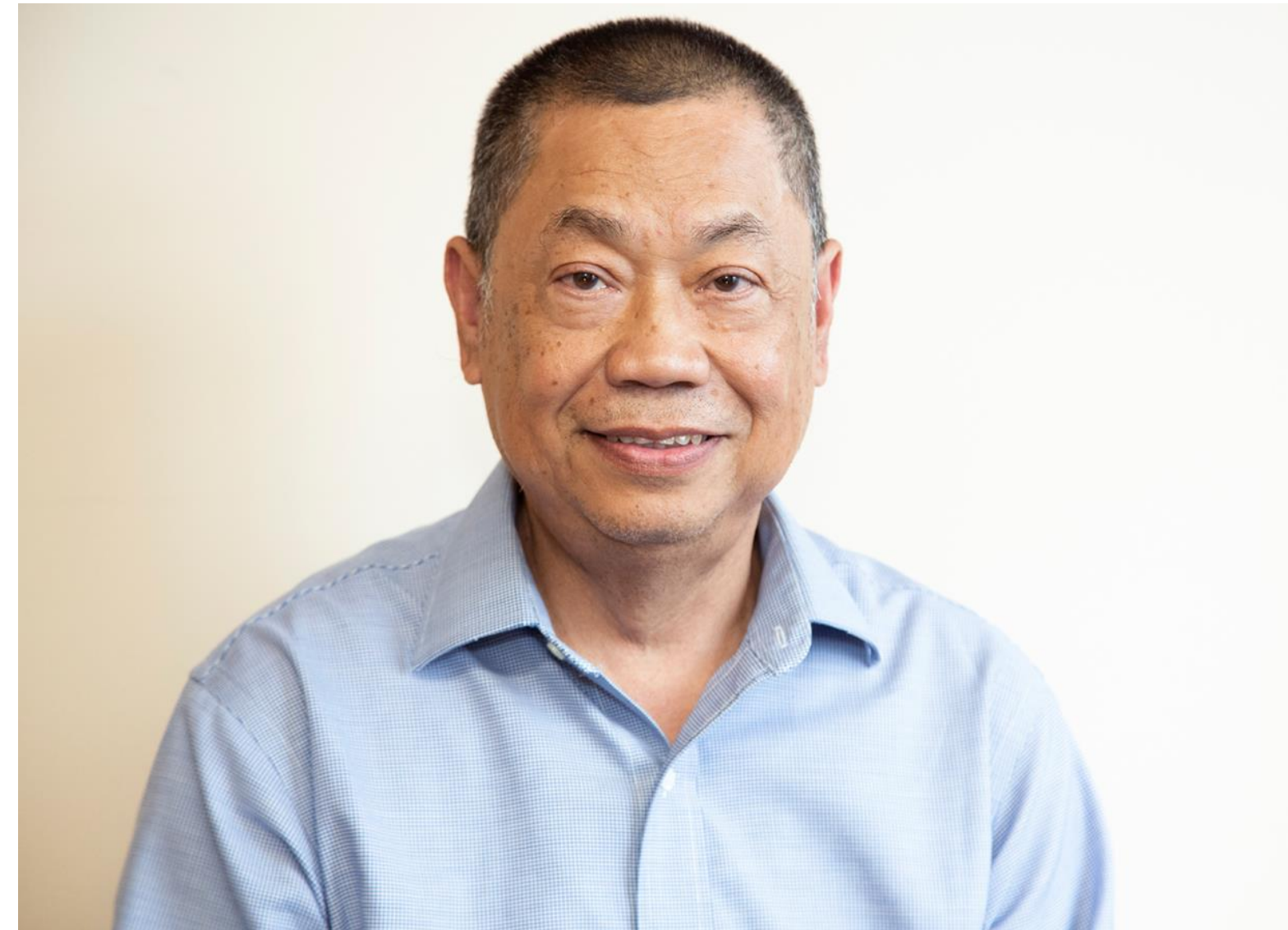
“What we also must have is a change in attitude. That is done one on one at an individual level and also at an institutional level. [We] also need a greater understanding of different communication needs and styles and not to stereotype people as a result of that.”

*- Person living with a disability*

- Revise policies & laws
- Respect personhood
- Respect rights
- Increase accountability
- Increase training
- Increase time
- Increase access to resources

# Communication: early stages

- Be patient and supportive
- Don't interrupt
- Give the person time to express themselves
- Don't talk about the person as if they aren't there
- Respect what they are saying
- Avoid asking questions which rely on good memory
- Communicate simple reminders by using notes
- Limit distractions as much as possible; find a quiet place to talk
- Avoid criticizing, correcting, or arguing
- Listen with your heart



# Communication: later stages

- Approach the person from the front and call the person by name
- Make eye contact and identify yourself clearly
- Avoid sudden movements
- Use simple sentences and ask one question at a time
- Ask questions which require a simple yes or no answer
- Avoid being too vague
- If repeating yourself, use the exact same words again
- Give visual cues
- Ask the person to point or gesture if they can't find the word
- Pay attention to your body and facial expressions
- Use a gentle, positive approach



Thank you to our funder

vancouver  
foundation

# Additional thanks

- [Inclusion Langley](#)
- [Inclusion BC](#)
- [DIVERSEcity Community Resources Society](#)
- [Richmond Society for Community Living](#)
- [Burnaby Access Advocacy Committee](#)
- [Plan BC](#)
- [PosAbilities](#)
- [The Disability Alliance](#)
- [The Bloom Group](#)
- [Dementia Advocacy Canada](#)
- [Burnaby Seniors Outreach Society](#)
- [Alzheimer's Café: BC Chapter](#)
- [Council of Senior Citizens Organizations of BC \(COSCO\)](#)
- [Canadian Hard of Hearing Association \(Chha-BC\)](#)
- And more!





# Would you like to participate?

- Focus groups
- Key informant interviews
- Stakeholder forums
- Tool development

Contact Jess Fehrenbacher at  
[jfehrenbacher@bcli.org](mailto:jfehrenbacher@bcli.org) to participate in  
the project.



# Let's stay in touch!

## WEBSITE:

[www.bcli.org/ccel](http://www.bcli.org/ccel)

## E-MAIL ADDRESS:

[jfehrenbacher@bcli.org](mailto:jfehrenbacher@bcli.org)

## SOCIAL MEDIA:

 @CCELElder Law

 @CanCentreforElderLaw

## PROJECT WEBPAGE:

[www.bcli.org/project/engaging-people-living-with-dementia-in-decision-making](http://www.bcli.org/project/engaging-people-living-with-dementia-in-decision-making)

## CCEL RESOURCES ON DECISION MAKING RIGHTS:

<https://www.bcli.org/project/health-care-decision-making-legal-rights-of-people-living-with-dementia>

# Discussion

1. What are you taking away from the presentation?
2. What challenges or successes do you see in your workplace for people to be involved in decision making?
3. What room for improvement do you think there is to include people living with disabilities and dementia in decision making?
4. What would you like to see in a tool for professionals and care partners to support decision making for people living with dementia?