

Mid-Term Evaluation Report: Engaging People Living with Dementia in Decision-Making

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1.0 Background

The Engaging People Living with Dementia in Decision Making project aims to change how healthcare decision-making is approached so that the rights of people living with dementia are respected and they participate as much as possible in the decisions that matter to them.

The Canadian Centre for Elder Law (CCEL) is evaluating this project to learn what is working well, what can be improved, and differences made.

2.0 Who participated in the evaluation?

- People living with dementia
- People with disabilities
- Family care partners
- Dementia Advisory Council (DAC)
- Key project partners
- Project Coordinator
- National Director
- Project records

3.0 Key Successes

- Validation that there is a need for this work
- Meaningful engagement of people with lived experience
- Rich data resulting from the consultation process to inform tool development

- Safe, respectful and accessible consultation environments
- Benefits of the consultations for participants (e.g. feeling connected, having voices heard, learning about rights)
- DAC's ability to guide the project, inform decision-making, and support consultations based on their lived experience

4.0 Key Challenges

- In-person consultation limitations due to pandemic
- Recruiting people living with dementia to participate
- Gaps in voices of hard-to-reach groups (e.g. Indigenous, those in later stages of dementia)
- Barriers to tools getting used (e.g. limited time of healthcare professionals, resistance to change, administration buy-in)

5.0 Conclusion

Findings show that the project has been well-received and is producing useful insights to inform tools to engage people living with dementia in decision-making. CCEL should continue to make ongoing project improvements based on feedback.