The NTG Canadian Consortium, along with the Reena organization, is undertaking an impactful 16-month project specifically focused on producing Canadian-oriented guidance materials to support adults with intellectual and developmental disabilities affected by dementia living in the community. This project builds on the success of Reena’s work with the Ontario Partnership on Aging and Developmental Disabilities (OPADD).

As recognized in Canada’s National Dementia Strategy, older adults with intellectual and developmental disabilities face many barriers to equitable care whilst aging and may be at higher risk for dementia. Furthermore, adults with Down syndrome, a form of intellectual disability, are at particularly high risk of young-onset dementia and may experience precipitous decline.

The project plans to update existing guidance documents to reflect the Canadian perspective, with the input of self-advocates, their families, and other care providers. Beneficiaries will include people with intellectual and developmental disabilities, families, caregivers, organizations, health and social care practitioners, senior services, and policy and decision-makers.

The project plans to hire a Senior Project Coordinator, create an Advisory Board, and establish a group of Provincial Project Facilitators in British Columbia, Saskatchewan, Manitoba, Ontario, and Quebec to carry on this work. Other provinces to be involved casually as opportunities arise.

The project plans to create adjunct resources to facilitate the dissemination of the updated guidance documents, namely:

- 3 webinar videos, one each for people with intellectual and developmental disabilities, one for staff, and one for families
- 3 booklets, one each for people with intellectual and developmental disabilities, one for staff, and one for families
- 3 FAQ sheets, one each for people with intellectual and developmental disabilities, one for staff, and one for families

The project will be led by a Senior Project Coordinator and overseen by an oversight committee drawn from the partnership of Reena and the NTG Canadian Consortium. Project principals include:

- Nancy Jokinen, Ph.D., UNBC School of Social Work, Prince George, BC
- Leslie Udell, Winnipeg, MB, organizational leader specializing in disability, aging, dementia, and end of life supports
- Sandy Stemp, COO of Reena, Toronto, Ontario