

Disclaimer:

Dementia Strategy Fund Project

What guides organizations' current dementia-related practice across four Canadian provinces?

The information contained in this PowerPoint presentation, is directly related to the work of the project on:

“Canadian Best Practice Guidance for Quality Community Supports and Care for Adults with Intellectual Disabilities and Dementia and Their Caregivers”

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What guides organizations' current dementia-related practice across four Canadian provinces?

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Outline



Background

- Adults with intellectual and developmental disabilities (IDD) are living longer and may experience age-related conditions such as dementia
- Little is known about dementia as it affects Canadians with IDD or their caregivers
- There is an absence of comprehensive Canadian practice guidelines to support daily, community living for adults with IDD affected by dementia and their caregivers





To collect information about what guides the current dementia-related practice of organizations who are providing supports or services to community-dwelling individuals with intellectual and developmental disabilities (IDD) who may be experiencing dementia across four Canadian provinces.

Methods

On-line cross-sectional survey

- 11 close-ended and 6 open-ended questions
- Distributed electronically via Survey Monkey

125 organizations in British Columbia, Manitoba, Ontario, and Saskatchewan were compiled as the target population

- A list of potential participants was created by members of the research team
- Reena sent an email invitation to each organization on our original email list to share information about the survey and request their participation on April 25, 2023 (survey closed on July 14, 2023)
- Reena tracked the number of surveys distributed by tracking the number of email invitations that was sent to organizations in all four provinces
- Reena initiated snowball sampling by requesting the original 125 email recipients to share the link to the survey with their contacts

Methods

Descriptive analysis was conducted based on data collected from all the study participants to describe the participating organizations and their current practice

- ❖ Content analysis was conducted to explore the current challenges and knowledge needs of the participating organizations based on the narrative responses to the open-ended questions on the survey. The emerging themes were reported.

Approval granted by the University of Manitoba Health Research Ethics Board



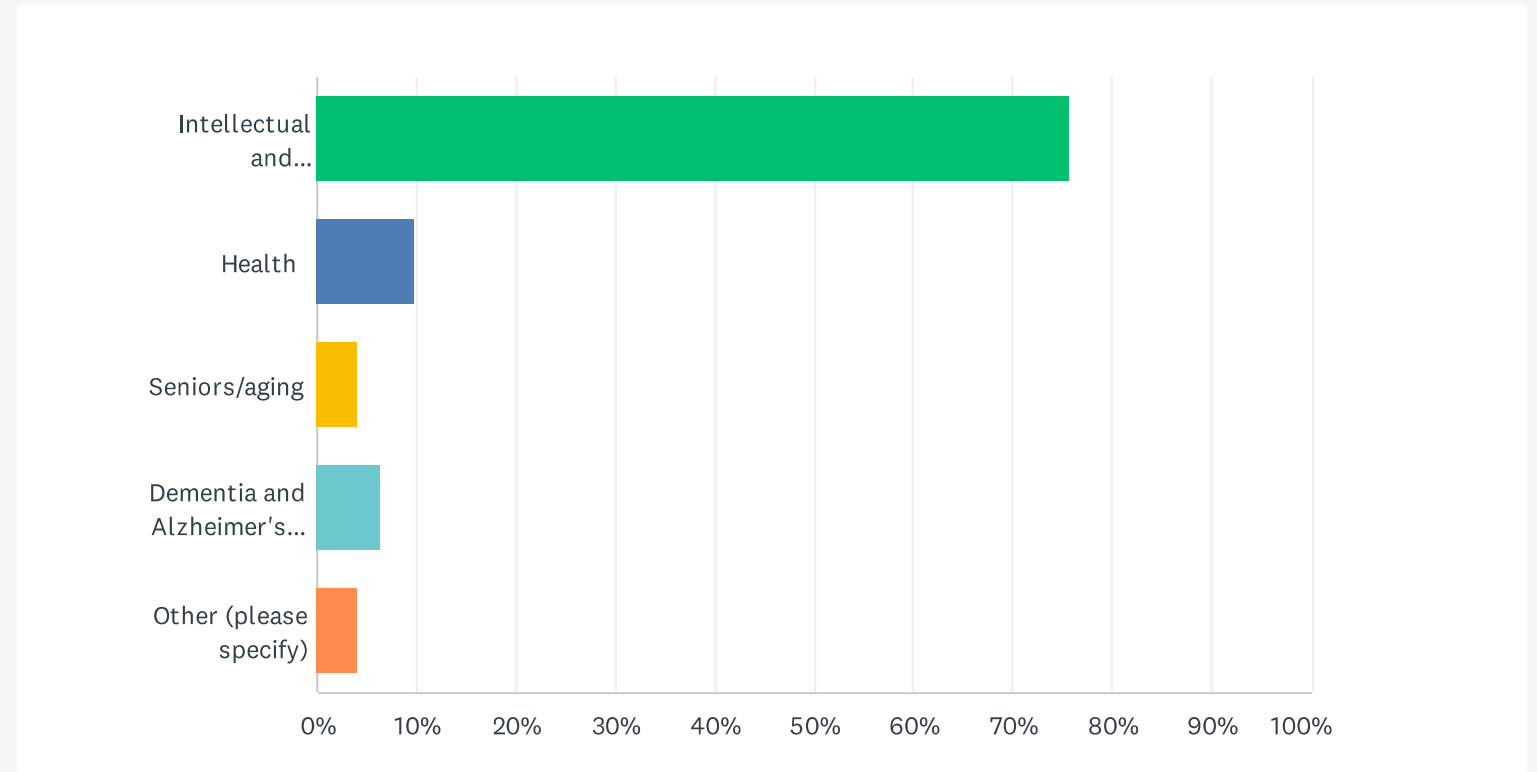
Results

173 people completed the survey

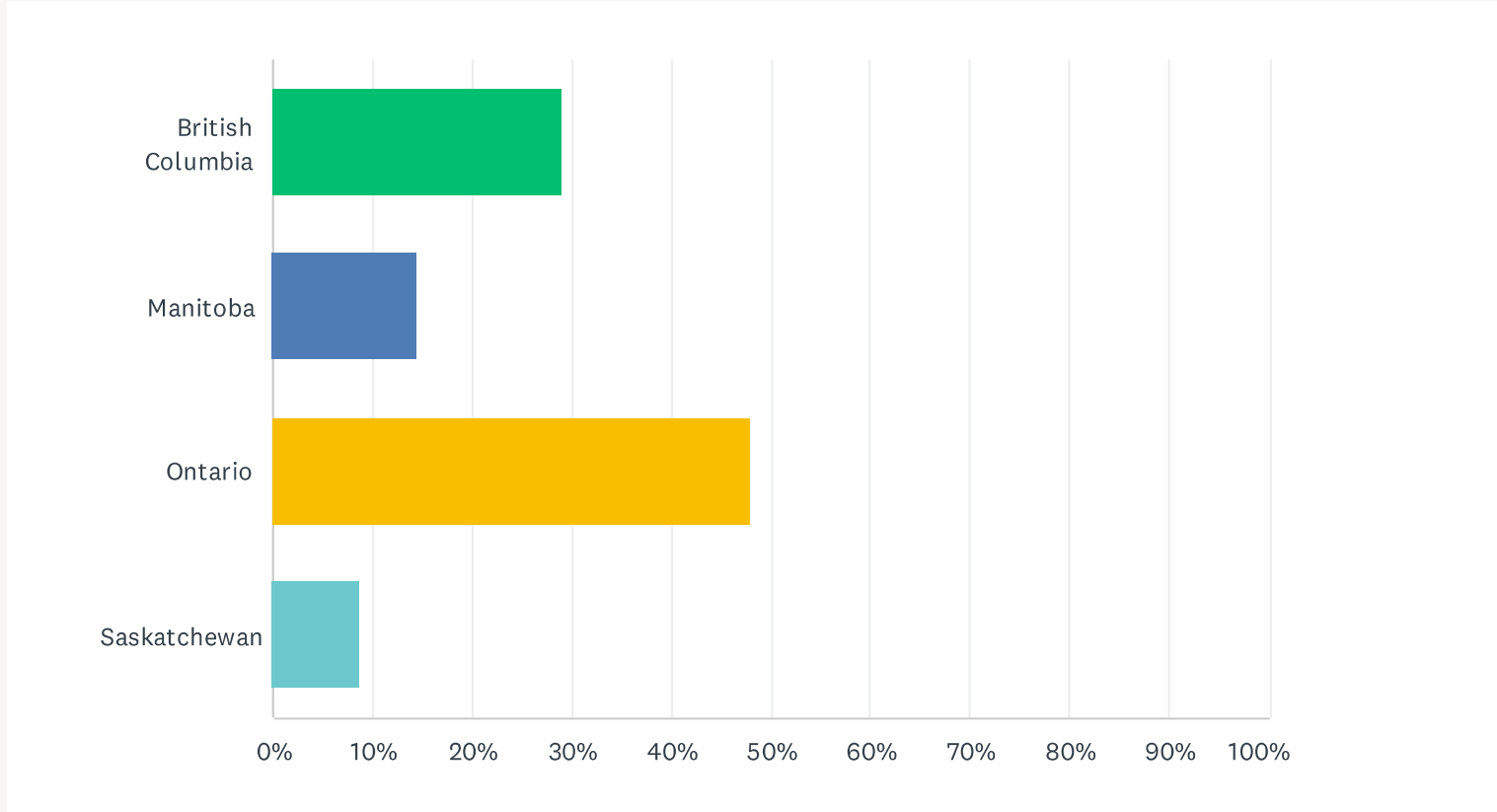
Responses to close-ended questions are presented in figures

Responses to open-ended questions are presented in tables

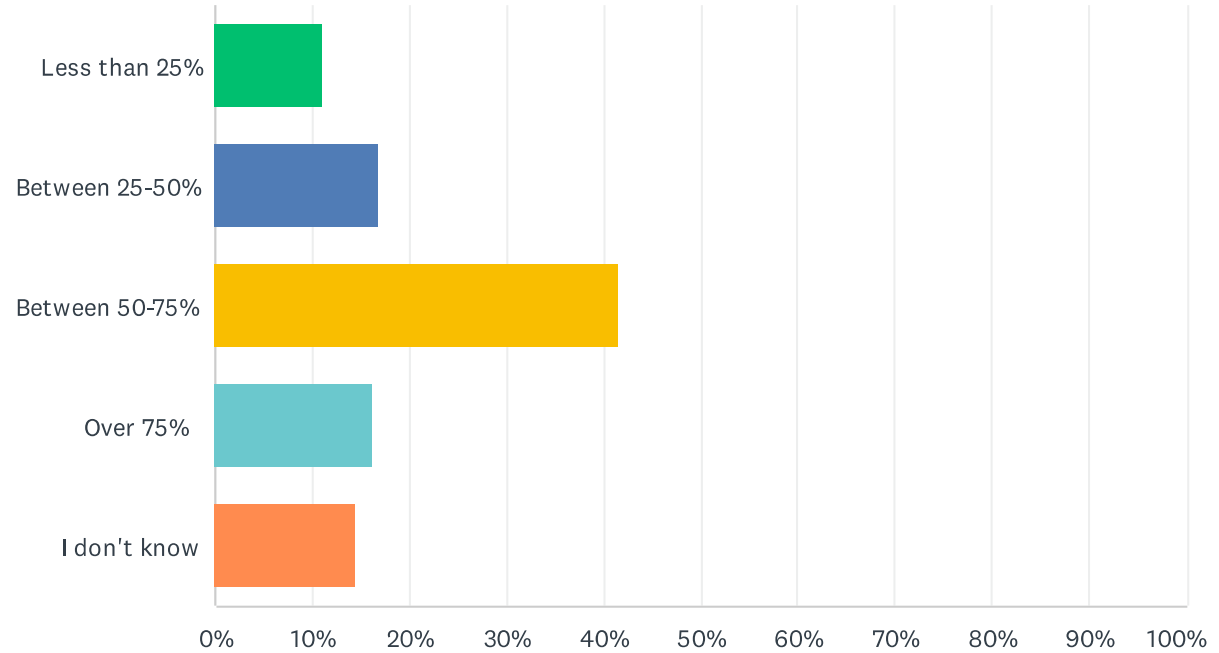
Organization by sector



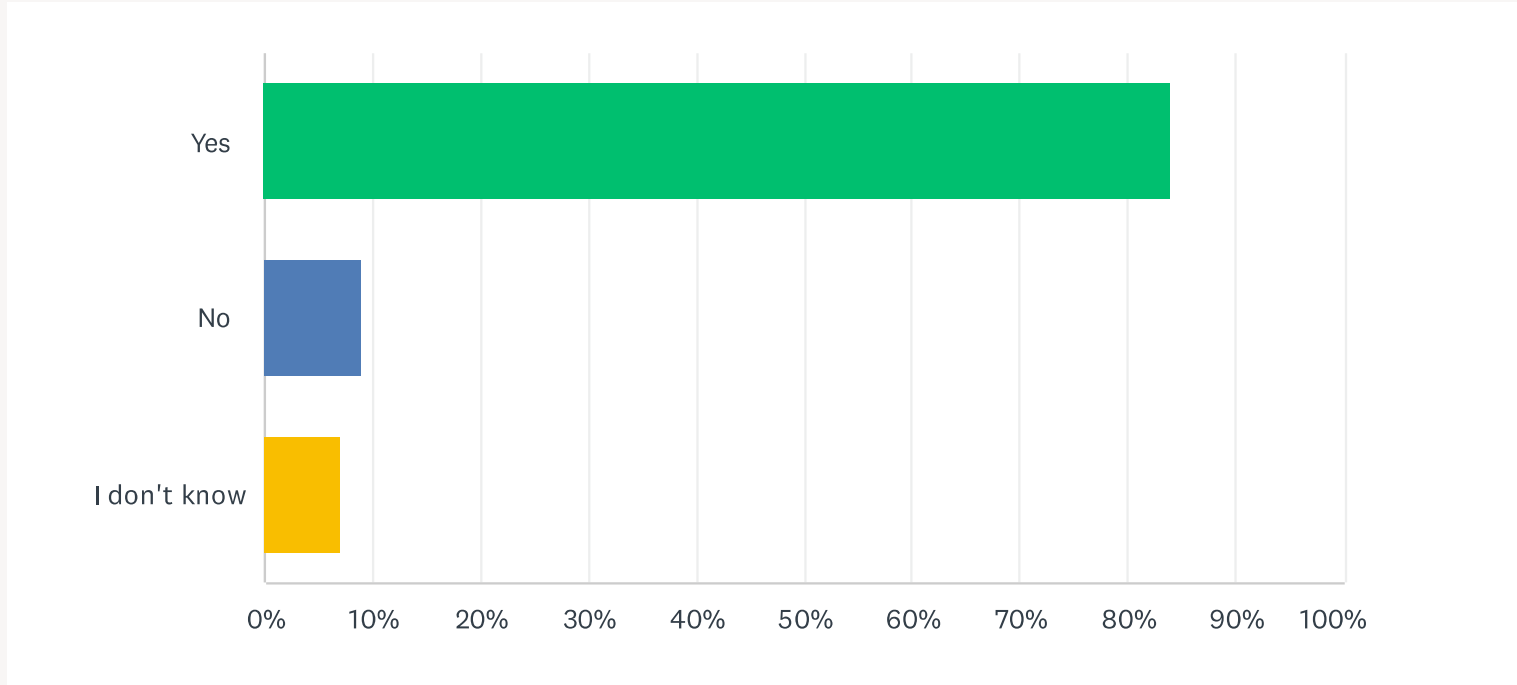
Organization by province



**Approximate
proportion of
supported
adults with
IDD over the
age of 40 years**



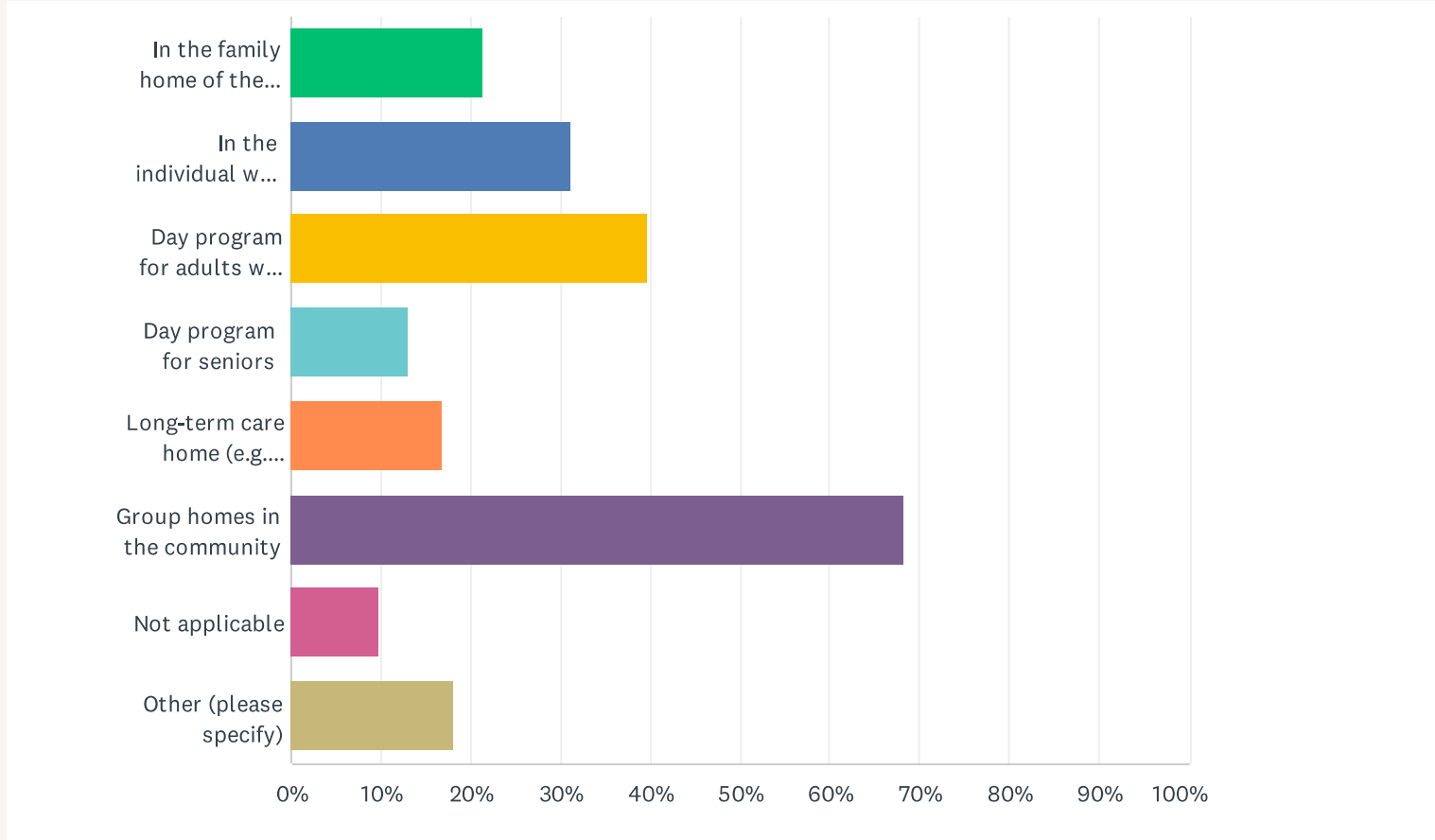
**Organizations
that provide
services to
adults with IDD
with probable
dementia**



Most commonly reported supports and services provided by organizations

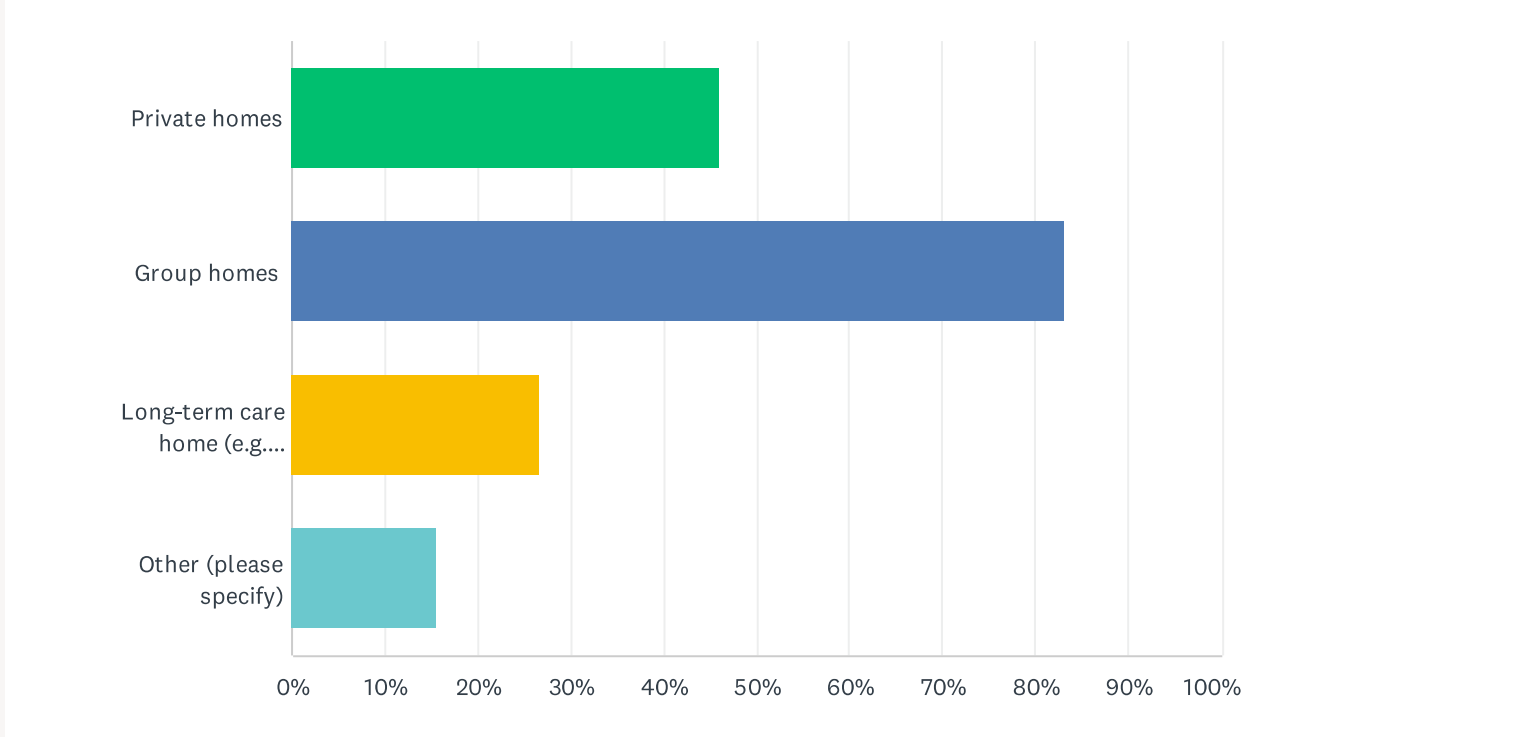
Description of supports and services provided by organizations	Number of Responses
Residential care and supports	48
Day program support and services	25
Home share/group home living	20
Clinical healthcare services	17
Education and training to staff, volunteers and family members	15
Community inclusion	14
Activity of daily living support	12
Specialized services (example: geriatric assessment and treatment services for mental health and cognition, memory clinic)	11
Employment support	11
Independent living program	10
Meaningful social and recreational activities	9

Location of provision of supports and services by organizations

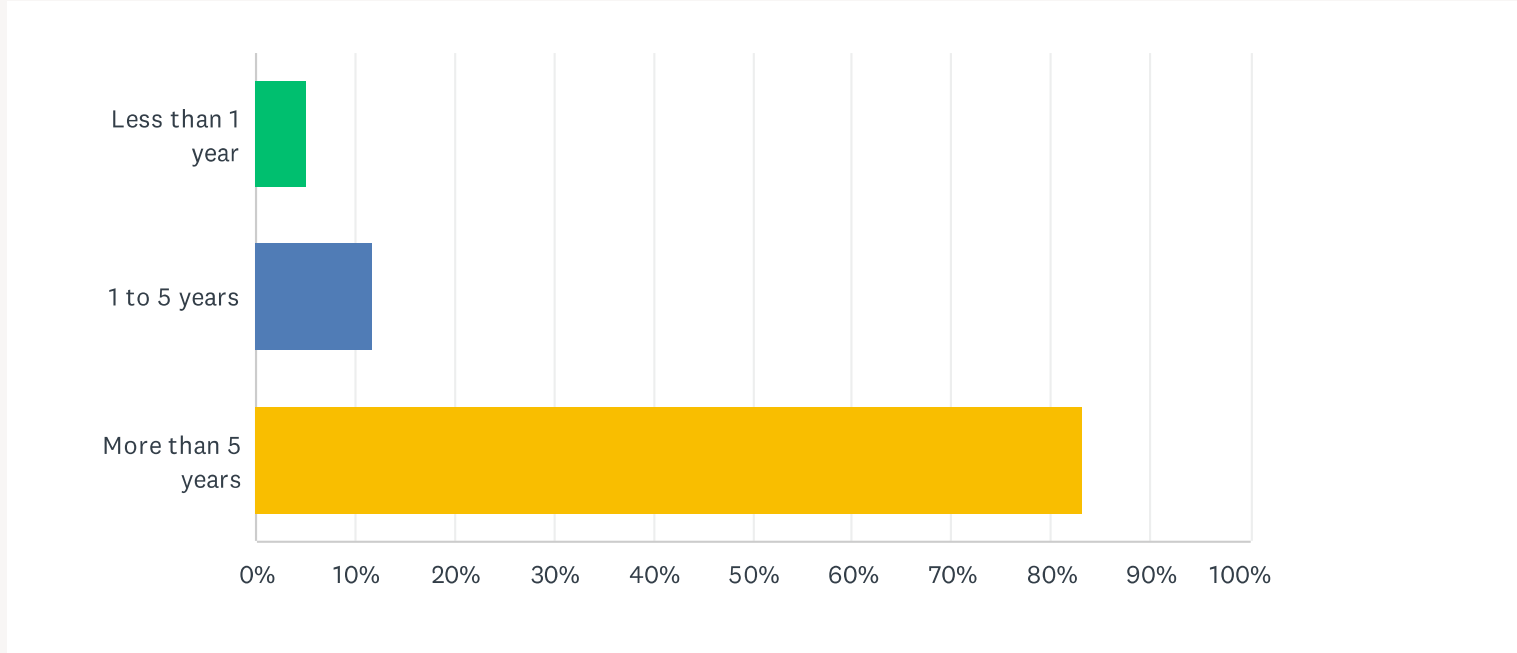




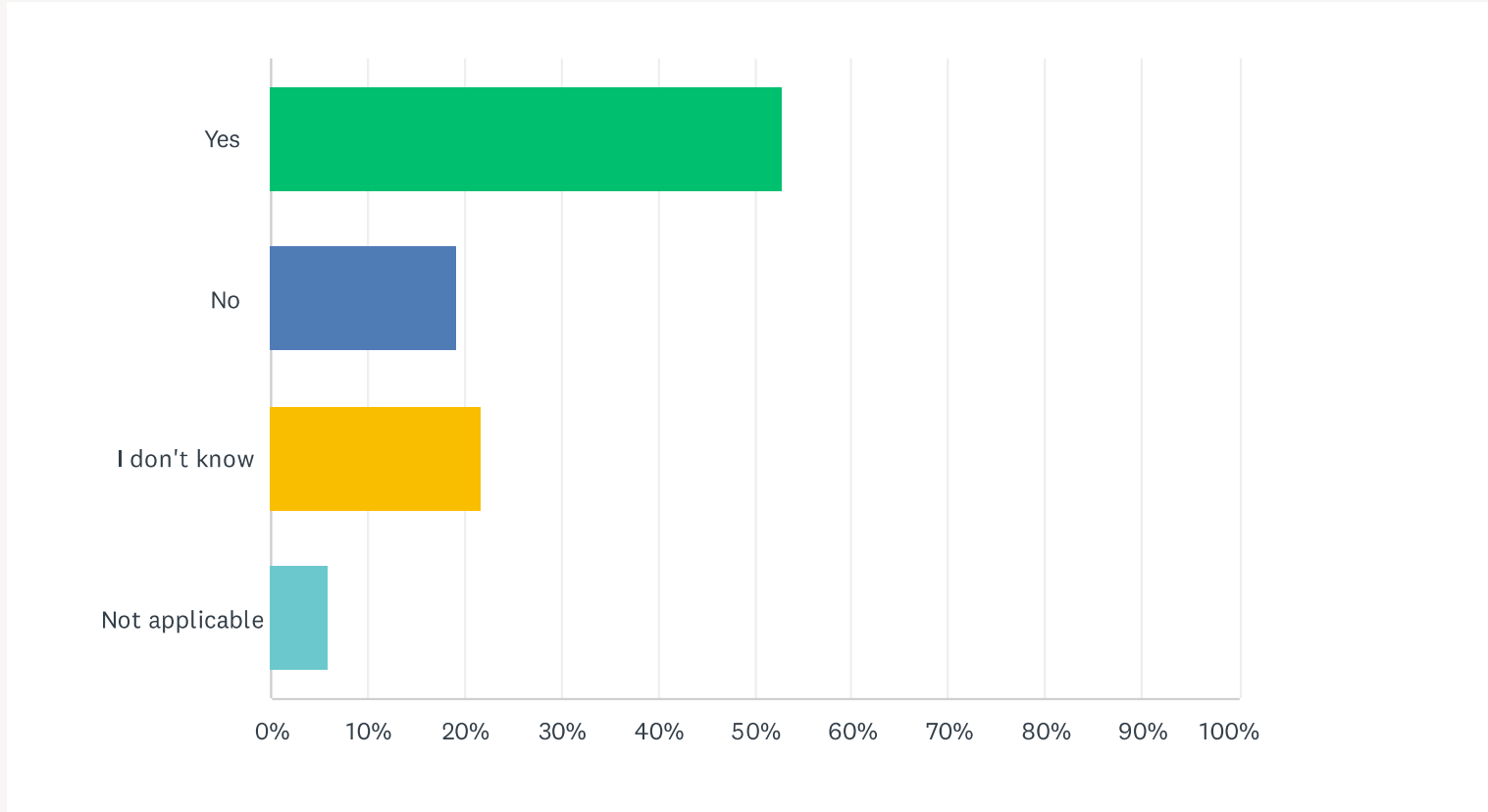
Location of residence of adults with IDD who are supported by organizations



Duration of provision of supports and services to adults with IDD



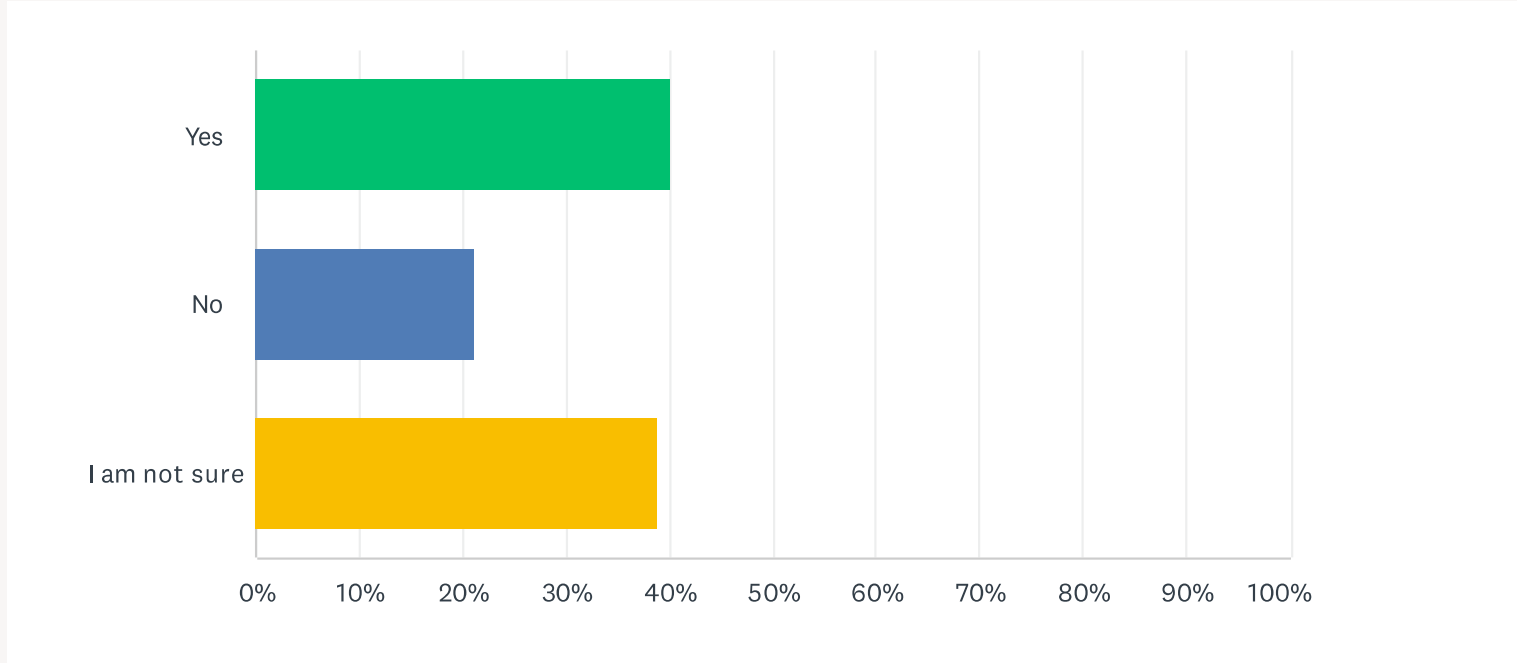
Use of dementia-related practice guidelines by organizations when providing supports or services to adults with IDD



Dementia-related practice guidelines followed by organizations

Dementia –related practice guidelines followed by organizations	Number of responses
National Task Group on Intellectual Disabilities and Dementia Practices	21 (31%)
Person- Centred Care	5 (7%)
Alzheimer Society	4 (6%)
DementiAbility	2 (3%)
Dementia screening tool, not specified	2 (3%)
Advice from physician	2 (3%)
Primary Care Guidelines for Physicians for Individuals with IDD	2 (3%)
Community Living B.C. guidelines	2 (3%)

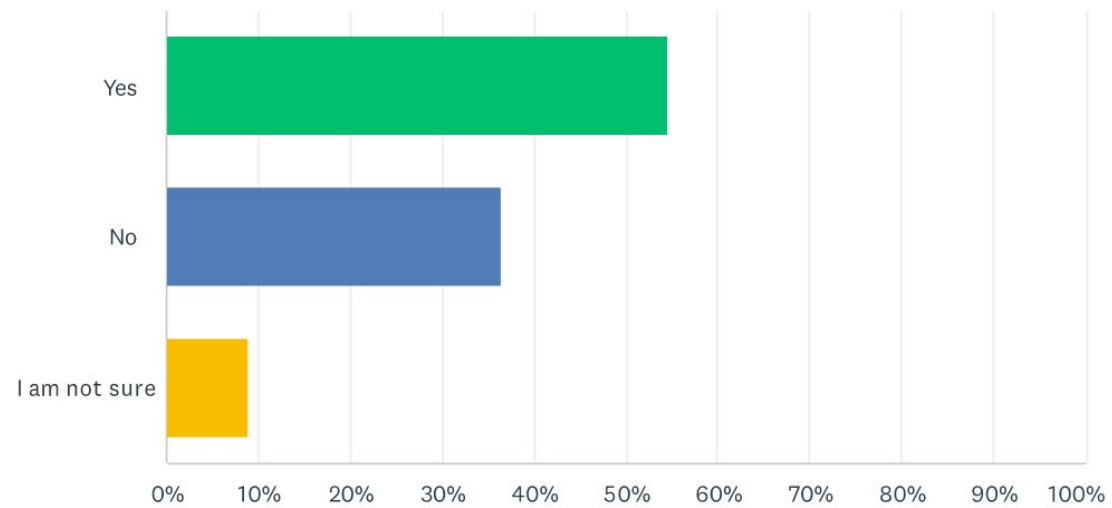
Awareness of organizations of dementia-related practice guidelines for the provision of supports or services to adults with IDD



Source of dementia-related practice guidelines used by organizations

Source of dementia-related practice guidelines	Number of responses
National Task Group	28 (48%)
Alzheimer Society	6 (10%)
Community Living B.C.	4 (7%)
Late Life Planning Guidelines (B.C.)	2 (3%)
Dementia Society	2 (3%)

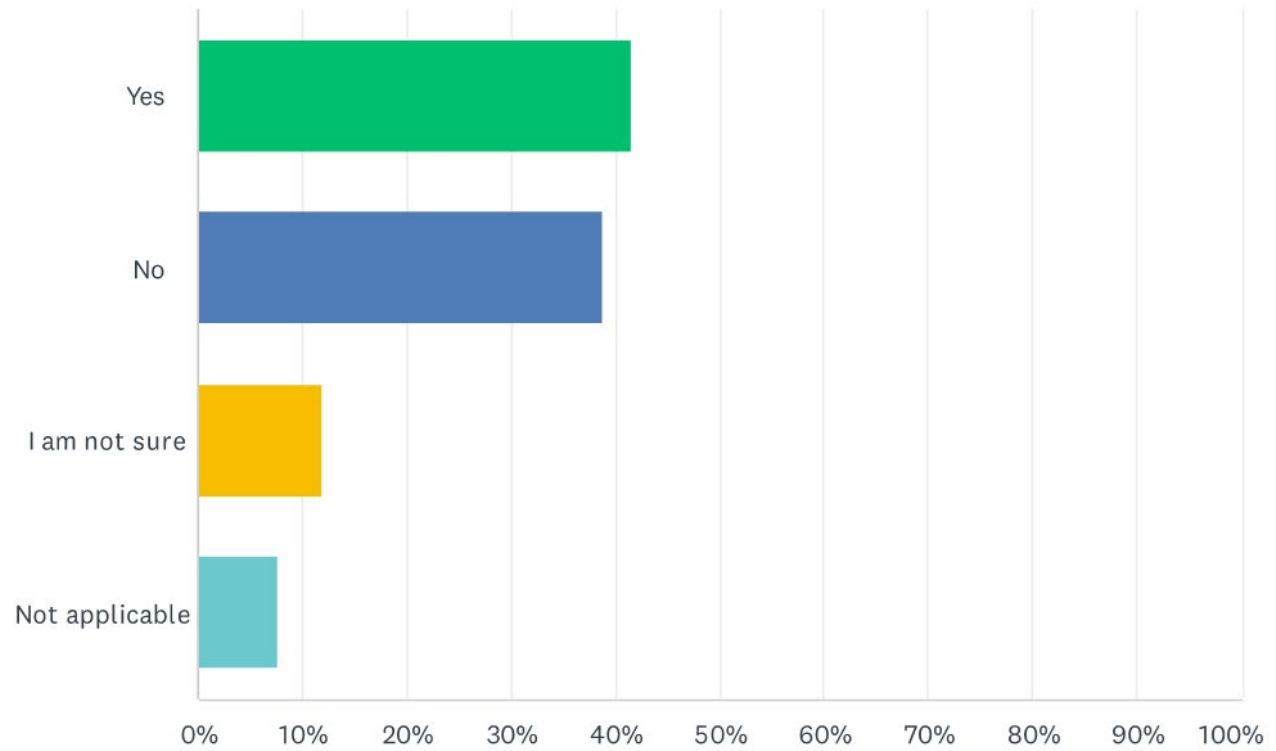
**Organizations that
offer dementia
education or training
to staff and/or
family members**



Description of education and training offered by organizations

Description of education and training offered by organizations	Number Of Responses
National Task Group	26
Alzheimer Society	12
Open Future Learning	6
Team of specialists	4
Staff	2
Inservice	2
Person-centred approach	2
Dementia training (not specified)	2

**Organizational use
of a
detection/screening
tool to detect early
warning signs of
dementia in adults
with IDD**



**Dementia
detection/screening
tool used by
organizations**

Detection/screening tool	Number Of Responses
National Task Group Early Detection and Screen for Dementia	34
Referral for psychology/psychiatry services	5

Resources used by organizations to guide practice for the provision of dementia-related supports or services

Name of dementia-related resource used by organizations	Number of responses
National Task Group	25
Alzheimer Society	17
Healthcare providers	12
Resources, not specified	10
Training, not specified	9


Main challenges experienced by organizations in their provision of dementia-related supports or services to adults with IDD

Main challenges experienced by organizations	Number of responses
Lack of education and training	28
Lack of funding	20
Lack of resources	18
Time to detect and diagnose dementia	10
Staffing issues (turnover, inadequate staff)	8
Lack of appropriate and accessible homes	8
Lack of access to professionals in the community	6
Unpredictability of dementia progression	6
Lack of consensus in future planning	6
Lack of value for individuals with IDD	5
Lack of time	5



**Learning
and
information
needs of
organization**

Learning and information needs of organizations	Number of responses
Training (not specified)	45
Dementia detection	31
Resources	21
How to modify home environments	12
Coping strategies	10
Information on dual diagnosis	9
Increased funding	8
Strategies to support staff	8
Trained staff retention	5



**Learning and
information
needs of
organizations'
leadership**

Learning and information needs of organizations' leadership	Number of responses
Education and training about dementia	39
Accurate and accessible resources	14
Increase funding	7
Information and access about dementia diagnostic services	7
Resource navigation	6
Strategies for intersectoral collaboration	6
Expertly trained staff	5
Supports for staff	5

Learning and information needs of organizations' direct support workers

Learning and information needs of organizations' direct support workers	Number of responses
Education and training about dementia and IDD	51
Resources (workshop, courses, best practice guidelines)	19
Information about how to detect dementia and early intervention	10
Information about how to manage behavioural concerns	9
Information about how to modify home environments	6

Additional concerns about organizations' experience with providing supports or services to adults with IDD and possible dementia

Additional concerns about organizations' experience	Number Of Responses
Lack of appropriate and accessible resources	8
Lack of funding for services	8
Lack of training on dementia and IDD	8
Collaboration between healthcare providers in a variety of settings	6
Lack of experienced staff	6
Lack of support for aging in place	4

Summary

Study sample was most representative of organizations operating within the intellectual and developmental disability sector in Ontario and British Columbia.

Most organizations provide supports or services to adults with IDD and possible dementia.

- For over 5 years
- Mostly residential care and support services
- In group homes in the community
- To adults with IDD who reside in group homes



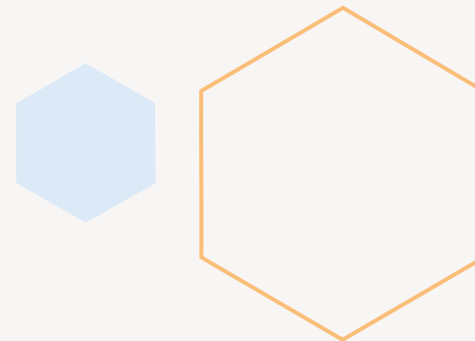
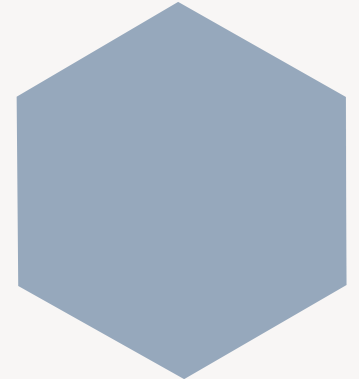
Summary

Most common guideline followed by organizations was from the National Task Group on Intellectual Disabilities and Dementia Practices

Many organizations offered dementia education or training, mostly from the National Task Group

A comparable number of organizations reported using and not using a detection/screening tool

NTG-EDSD was the most common detection/screening tool used



Take-aways



- Little representation of the prairie provinces (MB, SK)
- Awareness of guidelines was limited
- Despite being the most common response, a relatively small number of organizations named NTG as source of their training, education, or detection/screening tool
- Lack of education and training, funding, and resources is prevalent
- Learning and information needs centre around greater understanding of dementia (early detection, dual diagnosis, management)

References

- Haveman, M. J. (2004). Disease epidemiology and aging people with intellectual disabilities.
 - *Journal of Policy and Practice in Intellectual Disabilities*, 1(1), 16-23.
- Jokinen, N. (2019). Appendix G: Dementia and adults with intellectual / developmental disabilities. In Addendum to the CAHS Assessment on improving the quality of life and care of persons living with dementia and their caregivers (pp. 44-51). Ottawa, ON: Canadian Academy of Health Sciences.
- Sullivan, W.F. & Witherbee, S. (2018, April). Primary care of adults with intellectual and developmental disabilities. *Canadian Family Physician*, 64 (4) 254-279. Available from:
<https://www.cfp.ca/content/64/4/254>

Thank you

