



Disclaimer:

Dementia Strategy Fund Project



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”

Summary of Focus Group data: Dr. Nancy Jokinen and Leslie Udell



Focus Group & Individual Interview Findings



PHAC Dementia Strategy Fund Project

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

Advisory Committee Roundtable

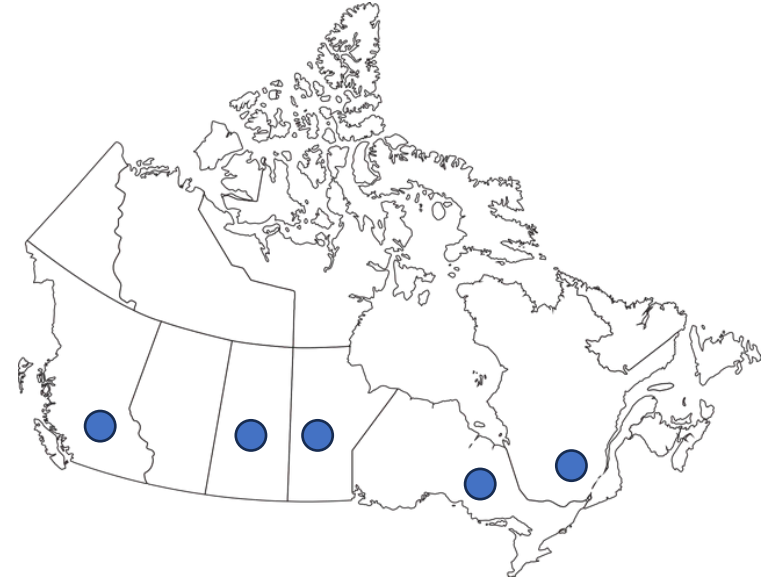
August 22, 2023

Leslie Udell, Nancy Jokinen

How did we do Focus Groups / Interviews?

- **Provincial Facilitators**

- Recruited through organizations known to us in 5 Provinces.
- BC, Saskatchewan, Manitoba, Ontario, Quebec.
- Provided with instructions.



- **Facilitator Responsibilities**

- Recruit participants.
- Complete demographics, consent.
- Record & conduct FGs or Interviews.
- Summarize & submit.



Who Did We Talk To?

- Adults with an intellectual disability
- Staff caregivers
- Family, Family-like
 - Example, long-term home share member.



Adults with Intellectual Disabilities Demographics



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Age Range in Years	Number of Participants
18 - 29	2
30 - 39	5
40 - 49	2
50 - 59	2
60 - 69	4
70+	1
Total	16

Who they knew had dementia:

- Parents/grandparents
- 3 lived with family with dementia
- A neighbour
- Their spouse, friend or housemate

Demographics - Staff

Age Range in Years	Number of Participants
18 - 29	1
30 - 39	10
40 - 49	10
50 - 59	9
60-69	5
Missing data	2
Total	37



Staff Aware of Dementia Care Guidelines for Organization

Province	Yes	No	Not sure
BC	3/8		5/8
Saskatchewan	-	9/9	-
Manitoba	3/7	2/7	2/7
Ontario	2/8	4/8	2/8
Quebec		5/5	

Demographics – Family / Family-like

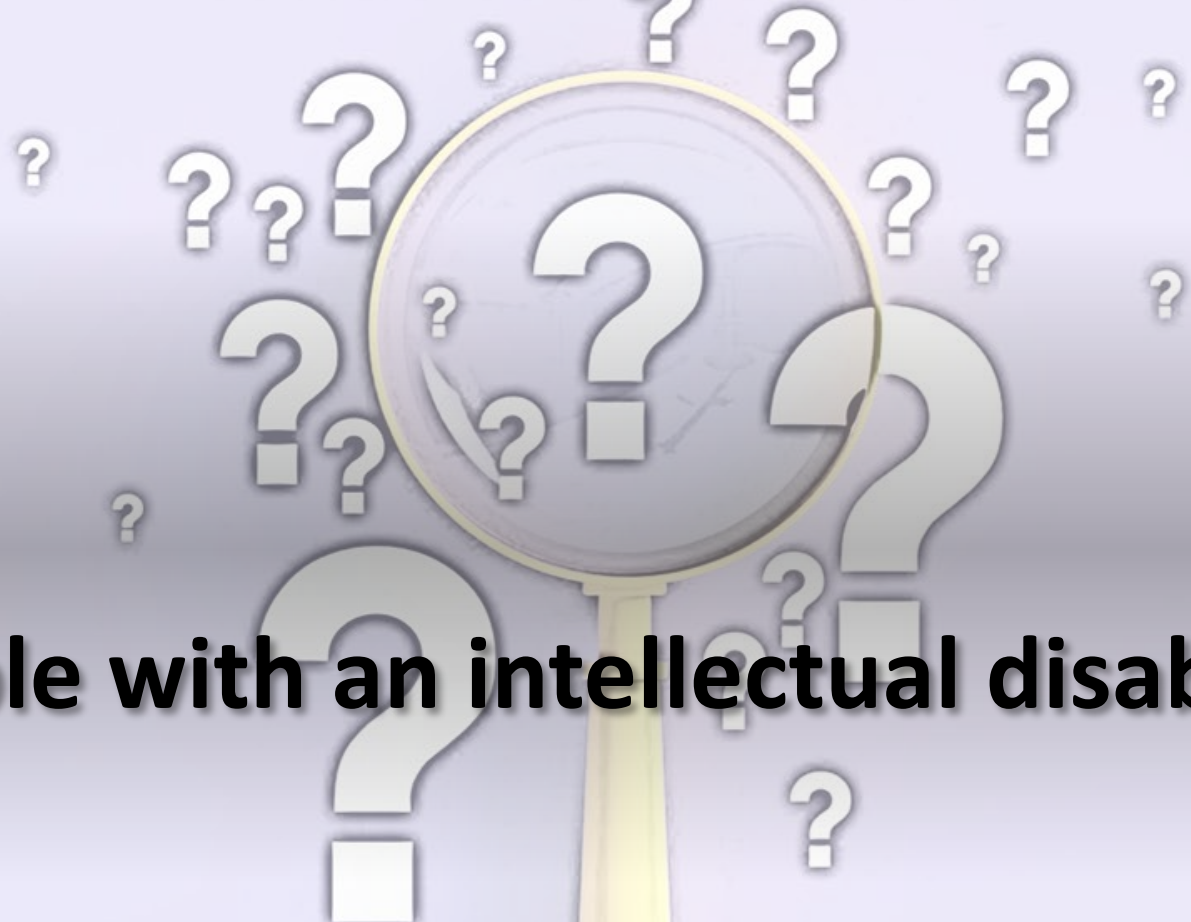


Age Range in Years	Number of Participants
50 - 59	6
60 - 69	7
70 - +	2
Total	15

Sources of Information Used

Books, Websites
Alzheimer Societies, ID/DD agencies

What We Learned



People with an intellectual disability

Adults with Intellectual Disabilities

How did dementia change people?

Commonly said	
Personality	Staying in their room
Forgets	Sleeping lots
Angry, confused	Not wanting to go out
Crying a lot	Not being able to walk
Needs more help to do things	



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Adults with Intellectual Disabilities

What was hard?

Common said	
Not understanding or knowing about dementia.	Person needing lots of help.
Having no information, resources, skills.	Trying to deal with behaviours, coping with all the crying
Feeling helpless, frustrated, guilty.	Taking things personally
Grief – watching the person's losses	Social isolation as roommate and/or caregiver.

Adults with Intellectual Disabilities

What was helpful?

Commonly said	
Patience	Seeing friends & visitors
Don't take it personally	Going outside
Using pictures & other visual cues	Having a break
Physical & verbal reassurances	Having in-home supports
Trying to help the person do things they used to enjoy	Help from other family members
Talking to the person	Professional help

Adults with Intellectual Disabilities

What information or training is needed?

What's Needed
How to help the person.
How to help calm the person down.
Support groups (e.g., Alzheimer Society).
I don't know.



Staff & Families – Changes in Person

- Common changes were noted by adults with intellectual disabilities, staff & family



- Differed from adults with intellectual disability in mentioning:
 - Verbal and physical aggression
 - Initially missing what was changing
 - Gradual onset of symptoms
 - Rapid progression(dementia diagnosis @ age 24)

What We Learned?

Staff?

Staff - What was helpful?

Commonly said	
Consistency & maintaining routines	Proactive versus reactive
Knowing the person's history	Sharing experiences, resources, support
Good communication	Dementia education & information
Early detection / screening	Collaboration
Unique: Roommate knowing person; written dementia support plans; dementia incorporated into organization's strategic plan	Training resources (e.g., NTG Canada Trainers, Open Futures, Teepa Snow videos, some Alzheimer Societies.)

Staff - What was hard?

Commonly said	
Lack information & training	Keeping safe & free of injury
Finding balance between safety & independence	Staffing (turnover, experience, pay)
Supporting families	Inflexible systems, funding
Emotional impact	Public Trustee
Negative impact on housemates	Limited, if any, supports for grieving
Managing responsive behaviors (e.g., aggression). No plan in place	Having good communication
Adapting to/seeing rapid change in abilities & transitions (e.g., moving)	

Staff - Training & information needs

What's needed
Training on age-related changes
General dementia training as well as training specific to adults with ID <ul style="list-style-type: none">• For families, adults with ID, and staff
Health care sector training about dementia and adults with ID
On the job training and mentoring by experienced staff.
Ongoing training opportunities (refreshers)
Work safety training (e.g., lifts, transfers, aggression)
Grief and grieving training & supports.
Easy access to a repository of tools



What We Learned

Family

Family - What was helpful?

Common Responses	
Having some experience with dementia	Respite, home care services
Reaching out to get support	Continuing day service
Information, education about dementia	Keeping involved
Seeing past the diagnosis	Finding professional allies
Person-centred care – letting her be her.	Having the right doctors
Staff – kind, devoted, knowledgeable	Palliative care
Planning in advance	Home death
Ability to stay in home	Family finances (e.g., massage therapy)
Proper help if moving residence	On-line information (e.g., Alz Society)

Family - What was hard?

Common Responses	
Reactive versus Proactive – no pre-plans	Lack of in-home spiritual supports
Organizational, municipal barriers	Lack of information, resources
Unresponsive/uneducated funder	Recognition of adverse drug reactions
Limited funding	Dealing with responsive behaviours
Staff turnover, low pay, no training	Cumulative, daily grief
Inflexibility of services	Night wakings
Waiting for equipment / services	Fatigue/exhaustion
Moving homes	Persistent advocacy for person

Family - Training & information needs

Common Responses	
Understanding & supporting adults with dementia (family, staff, healthcare)	Effective care strategies – e.g., Massage therapy, hairstylists..
For doctors, healthcare professionals	Ethical Issues
Housemates having options	Learning, sharing with other families
House manager knowledgeable, knows best practices	Advanced care planning
Managing responsive behaviours.	Palliative care - Supporting people through to death
Creating a safe home environment	Dementia website with resources
Environmental modifications	Access-knowledge community services

Health Care Supports & Services

- Participants with an intellectual disability made no comments concerning healthcare supports and services.
- Family and Staff made several comments on various aspects of healthcare.
- **Positive comments** included those about:
 - **Family doctors.**
 - **Palliative Care**
 - **Specialized nursing supports.**
 - **Availability of clinical services.**
 - **The 45+ Clinic at Surrey Place.**



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There were, however, many critical comments about health care voiced. Some reflect what others in the general population face, others were not perceived as such.

Health Care and Dementia Diagnosis

- Hard to get a diagnosis
 - Availability in one group of participants...
- Sometimes people never get a diagnosis.
- Diagnostic overshadowing

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- Only one positive story of getting a diagnosis (45+ clinic Surrey Place).



ASSESSMENT

Family / Staff - Health Care Comments

- **Unresponsive** health care systems & professionals
- Health care professionals with **no knowledge** of dementia & ID
- **Long waits** to access services, needed equipment
- **Emergency services dismissive** of concerns
- Some **rural services** – ½ doctor – needing to travel at other times.
- **Refusals** to assess sudden change in behaviours
- **Inadequate home care** services



Stories

Connecting with real lives