



Aging Project 2018/19 Update DECEMBER 2019

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**Canadian
Frailty
Network**

**Réseau canadien
des soins aux
personnes fragilisées**



CIHR IRSC
Canadian Institutes of
Health Research Instituts de recherche
en santé du Canada



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Overview

Our earlier work has shown that adults with IDD experience higher rates of frailty, use aging care services at earlier ages, and the subset aged 65+ years is increasing. However, once frail does not mean always frail – stability and improvement are viable goals of care, and frail adults can be successfully supported in the community.

Our international consensus statement on how best to support adults with IDD as they become frail identifies seven recommended actions:

1. Frailty must be considered earlier
2. Improvement and maintenance are viable goals
3. Intersectoral collaboration is needed
4. Safety is a priority
5. Planning for the future is important
6. Informal and formal caregivers have needs
7. The evidence base must be grown.

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ORIGINAL ARTICLE

How best to support individuals with IDD as they become frail: Development of a consensus statement

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Abstract
Background: While higher rates and earlier onset of frailty have been reported among adults with intellectual and developmental disabilities (IDD), research on how best to support these individuals is lacking.
Method: An international consultation relied on three consensus building methods: the Nominal Group Technique, an Intra-consensus conference approach, and a Delphi survey.
Results: There is agreement that person-centered planning and aging in place should be guiding principles. Frailty must be considered earlier than in the general population with the recognition that improvement and maintenance are viable goals. Intersectoral collaboration is needed to coordinate assessments and actions. Safety and planning for the future are important planning considerations, as are the needs of caregivers. Ongoing research is needed.
Conclusion: The statement offers guidance to respond to frailty among adults with IDD and fosters ongoing exchange internationally on best practice. As new evidence emerges, the statement should be revisited and revised.

KEYWORDS: frailty, consensus, aging, intellectual disabilities, developmental disabilities

1 | INTRODUCTION

Concern for age-related health decline experienced by adults with intellectual and developmental disabilities (IDD) has increased as this population is living longer (Ouellette-Kuntz, Martin, & McCallion, 2015). While the tendency has been to consider health problems individually, there is increasing awareness of the importance of measuring the combined effects of multiple changes and risks at an individual age. Frailty provides such a measure (Clegg, Young, Alty, Rikart, & Rockwood, 2013; Fried et al., 2001; Rockwood, Hogan, & MacKnight, 2008; Schoof, Everhart, Mittal, Rockwood, & Eklund, 2015). Frailty is a multi-dimensional state of vulnerability with cognitive, social, psychological and biological deficits, as well as environmental aspects associated with aging and adverse outcomes (e.g., falls, hospitalization, institutionalization and mortality) (Clegg et al., 2013; Cole, Cooper, & Smeets, 2015). There are two main approaches to measuring frailty: the accumulation of deficits approach (Rockwood et al., 2005) and the phenotype approach (Fried et al., 2001). Research related to frailty among adults with IDD is relatively new, and to date has only been conducted by three research teams internationally (McCallion, Martin, & Ouellette-Kuntz, 2015) providing a handful of validated measures of frailty for use in this population (Bakker, Rindere, Zolinger, Kataljani, & Walter, 2013; McCallion, Ouellette-Kuntz, & Martin, 2015; Schoof, Winkels, Rockwood, Everhart, & Eklund, 2015). These measures also identify persons who are "pre-frail", pre-frailty is an intermediate state

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Work is underway by our international frailty consensus group to translate, disseminate and mobilize knowledge related to actions 1 to 6. This report focusses action #3 – intersectoral collaboration is needed.

In this report, we describe the activities undertaken over the past year and a half to understand effective intersectoral collaboration for the care of older adults with IDD who are frail and to disseminate relevant knowledge to key stakeholders including caregivers and adults with IDD.

The report is organized around three objectives:

1. Understand intersectoral collaboration to support actions related to the prevention and management of frailty.
2. Translate, disseminate, and mobilize knowledge.
3. Understand stakeholder information needs related to frailty and intersectoral collaboration, and their interest in various forms of knowledge mobilization.

For each objective, we describe the work we undertook and the outcomes of our activities.

The report also includes a list of other dissemination activities for the past 18 months related to our work in aging, frailty and IDD and a list of the trainees who have contributed to the work.

Objective 1

Understand intersectoral collaboration to support actions related to the prevention and management of frailty

We partnered with Reena and Mary Centre –two developmental service agencies in Ontario - to understand intersectoral collaboration in action by undertaking a case study of the agencies' efforts to support frail or pre-frail adults with IDD through collaboration with home care services.

A scoping review was conducted to identify key components of effective intersectoral collaboration currently used in the health sector. This review identified over twenty different factors contributing to successful intersectoral collaboration, which could be grouped under six key conditions: necessity, opportunity, capacity, relationships, planned action, and sustained outcomes.

Framework for understanding intersectoral collaboration

Necessity	Opportunity	Capacity	Relationships	Actions	Sustainability
<ul style="list-style-type: none"> • Realize need to work together • Shared vision, mission, goals • Shared values, ideologies • Range of perspectives 	<ul style="list-style-type: none"> • Organizational support • Supportive political & policy environment • Commitment from key stakeholders • Actively involves persons with lived experience • Early stakeholders engagement 	<ul style="list-style-type: none"> • Formal arrangements • Knowledge & skills • Resources • Equal distribution of power • Stakeholder engagement in decision-making • Linkages across and within sectors 	<ul style="list-style-type: none"> • Clarity of partnership • Trust, respect • Early investment in alliance-building • Effective leadership, champions • Shared accountability & rewards • Interpersonal skills • Effective & active communication 	<ul style="list-style-type: none"> • Clear roles, responsibilities, expectations • Actions feasibly implemented & evaluated • Relevant visible results 	<ul style="list-style-type: none"> • Plans for monitoring & sustaining outcomes • Models, processes, & tools to sustain collaboration

Adapted from Martin, Deck, Barabash, & Ouellette-Kuntz (in press). Intersectoral collaboration in the context of supporting adults with intellectual and developmental disabilities who are frail. *Research and Practice in Intellectual and Developmental Disabilities*. doi: 10.1080/23297018.2019.1710723

We interviewed 23 people, including adults with IDD, family members, developmental services workers, and health care workers. We learned that, with the exception of individuals and families not discussing “sustained outcomes”, all participants touched on facilitators and barriers across the six key conditions. Our study also revealed that, when it comes to collaborative ventures between social and health care teams, use of resources and tools that both facilitate and promote these conditions should be prioritized.

Conditions for Effective Intersectoral Action by Participant

Conditions for Effective Intersectoral Action		Participant Type		
		Individuals & Families	DS sector	Health sector
Necessity		✓	✓	✓
	Recognize the need to work together	×	✓	✓
	Philosophies conducive to collaboration	×	✓	✓
	Shared goals and values	✓	✓	✓
	Range of perspectives present	✓	✓	✓
Opportunity		✓	✓	✓
	Supportive organization	×	✓	✓
	Supportive political & policy environment	×	×	✓
	Strategic stakeholders are committed	×	✓	✓
	Persons with lived experience are active partners	✓		✓
Capacity		✓	✓	✓
	Partnership arrangements in place	×	✓	✓
	Horizontal linkages across sectors	×	✓	✓
	Vertical linkages within sectors	×	✓	✓
	Power is equally distributed	×	✓	✓
	Key partners engaged in early decisions	✓	✓	✓
	Stakeholders engaged in decision-making	✓	✓	✓
	Shared leadership, accountability, and rewards	×	✓	✓
Relationships		✓	✓	✓
	Clearly defined, built on trust	×	✓	✓
	Invest in alliance-building/consensus early on	✓	✓	✓
	Work well together	✓	✓	✓
	Champions in the partnership	×	✓	✓
	Active/Effective communication between partners	✓	✓	✓
Planned action		✓	✓	✓
	Clear roles and responsibilities	×	✓	✓
	Actions can be implemented and evaluated	×	✓	✓
	Actions relevant to concrete goals/visible results	✓	✓	✓
Sustained outcomes		×	✓	✓
	Plans to monitor and sustain outcomes	×	✓	✓
	Models/Processes/Tools to support collaboration	×	✓	×

Adapted from Deck, Barabash, Martin, & Ouellette-Kuntz (2019). Supporting adults with IDD who are frail: intersectoral collaboration in action. *2019 National Conference on Frailty: Innovation and Collaboration for impact* (September 26-27, 2019, Toronto, ON).

Objective 2

Translate, disseminate, and mobilize knowledge

Engaging with knowledge users throughout the research process is important to produce results and products that are likely to be both directly relevant to and adopted by knowledge users. We worked to engaged audiences through workshop presentations and developing resources.

To increase awareness of both frailty in adults with IDD and components of effective intersectoral collaboration among service providers and caregivers, we produced **infographics** which we animated into short **videos**. The materials on frailty were translated from English to French and Spanish; and the materials on intersectoral collaboration were translated from English to French. Infographics were developed with input from service providers and caregivers.

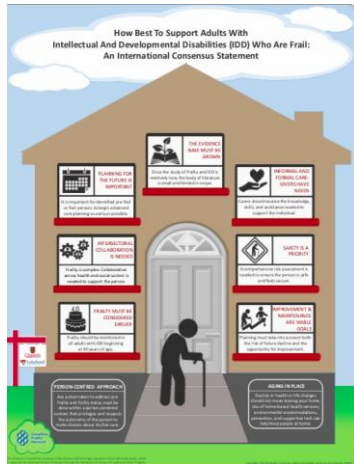
With input from self-advocates, we produced two **workbooks** to help adults with IDD appreciate their role when supported through intersectoral collaboration and to understand actions to take when identified as frail.

We produced two **reports** for Reena and Mary Centre and continued to present our work at scientific meeting (**oral presentations** and **posters**) and to publish our findings from the above activities and related studies in peer reviewed **journals**.

Resources

We have developed a number of resources (available in English and French) related to frailty and intersectoral collaboration available through www.mapsresearch.ca.

Infographics:



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©Martin, Deck, Barabash, & Ouellette-Kuntz (2019)

Videos:



©Barabash, Ouellette-Kuntz, & Martin (2019)



©Barabash, Martin, & Ouellette-Kuntz (2019)

Workbooks:



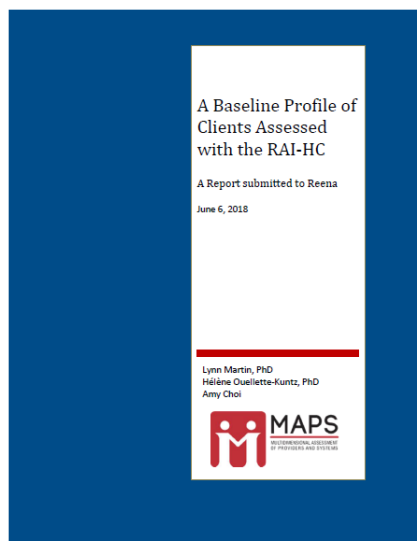
©Buttar, Martin, Barabash, & Ouellette-Kuntz (2019)



©Boyd, Martin, Barabash & Ouellette-Kuntz (2019)

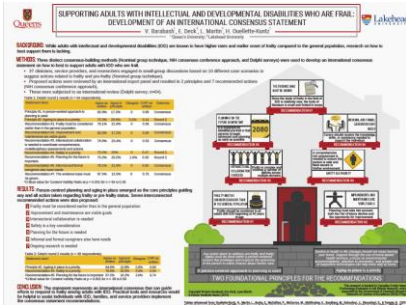
Reports:

Two reports were submitted to Reena and Mary Centre.

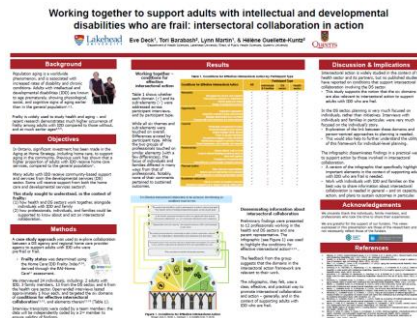


Scientific Activity: Posters

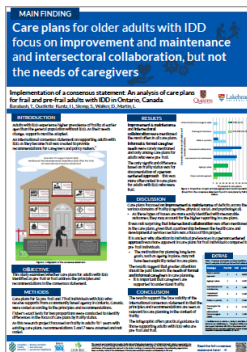
We presented posters at regional, provincial, national, and international conferences.



Barabash, V., Deck, E., Martin, L., & Ouellette-Kuntz, H. (2019). Supporting adults with intellectual and developmental disabilities who are frail: development of an international consensus statement. 2019 Showcase of Health Research, Centre for Applied Health Research at St. Joseph's Care Group (February 8, 2019, Thunder Bay, ON).



Deck, E., Barabash, T., Martin, L., & Ouellette-Kuntz, H. Working together to support adults with IDD who are frail: intersectoral collaboration in action (2019). Ontario Association for Developmental Disabilities (OADD) Research Special Interest Group (RSIG) Research Day, April 11, 2019 (Niagara Falls, ON).



Barabash, T., Ouellette-Kuntz, H., Stemp, S., Walker, D., & Martin, L. (2019). Implementation of a consensus statement: an analysis of care plans for frail and pre-frail adults with IDD in Ontario, Canada. *The World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities* (August 6-9, 2019, Glasgow, Scotland).



Deck, E., Barabash, T., Martin, L., & Ouellette-Kuntz, H. (2019). Supporting adults with IDD who are frail: intersectoral collaboration in action. 2019 National Conference on Frailty: Innovation and Collaboration for impact (September 26-27, 2019, Toronto, ON).

Objective 3

Understand stakeholder information needs related to frailty and intersectoral collaboration, and their interest in various forms of knowledge mobilization

We consulted with different groups to better understand the information needs of key stakeholders, including with:

1. **iCAN! Social Network**

(<http://tbfm.ca/pages/view/ican-social-network>)



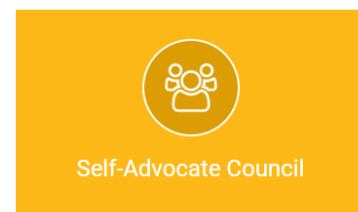
2. **Ontario Partnership on Aging and Developmental Disabilities**

(<http://www.reena.org/training/opadd/>)



3. **Self-advocate council, Community Living Thunder Bay**

(<http://www.cltb.ca/self-advocacy>)



4. **Seniors Health Knowledge Network**

(<https://shrtn.on.ca/seniors-health-knowledge-network>)



Workshops and webinars were held to further understand the interest in different forms of knowledge mobilization:

IASSIDD, August 2019

The team presented a workshop on the recommended action to address frailty in adults with IDD at an Academy event of the International Association for the Scientific Study of Intellectual and Developmental Disabilities in Glasgow. Workshop participants were service providers, clinicians and researchers from the United Kingdom, Singapore, Taiwan, New Zealand, and Australia. They provided input on the clarity, and completeness of the infographics.



Interactive webinar, November 2019

Hélène Ouellette-Kuntz, Lynn Martin, and Tori Barabash presented an interactive webinar on using intersectoral collaboration to support adults with IDD who are frail.



Over 100 people attend the webinar offered through the Seniors Health Knowledge Network (SHKN). Participants from across Canada included caregivers, policy makers, and direct service providers working in health, aging and/or IDD sectors.



Participant polling confirmed the need for tools to enhance intersectoral collaboration. Most indicated they preferred workbooks or guides to help them in these efforts.

Symposium TPSC - Promotion de la santé de la tête aux pieds des personnes ayant une DI, December 2019

On behalf of team members, Hélène Ouellette-Kuntz provided a workshop in French on frailty and aging in individuals with intellectual and developmental disability to developmental service providers in eastern Ontario. Approximately 30 individuals participated. Interestingly, these francophones indicated a preference for online courses to facilitate learning about frailty including intersectoral collaboration.

Other Dissemination Activities

Oral presentations

In 2019, we gave presentations based on our previous work on frailty at two international conferences.

IASSIDD World Congress, August 6-9, 2019 (Glasgow, Scotland)

Frailty is a health condition with multiple causes and contributors. It is characterised by diminished strength, endurance, and reduced physiologic function. Frailty is associated with numerous adverse health outcomes including disability, sarcopenia, increased falls risk, decreased mobility, reduced independence, institutionalisation, hospitalisation, higher medication use, prolonged recovery and premature death. A literature review of current research evidence was performed to investigate why individuals with IDD are predisposed to early onset frailty and what reasonable adjustments can be introduced to support aging in place for this cohort. Research has revealed that individuals with IDD should be monitored for frailty at a younger age, particularly those at a heightened risk of accumulating frailty deficits at an increased rate. The deficit accumulation conceptual model of frailty has been operationalized through the creation of Frailty Indices, some designed for specific use in the IDD population. Studies have also found a correlation between high Frailty Index scores and certain inflammation bio markers. The detection of frailty can prompt appropriate actions which may improve care and life quality outcomes. However, there is a scarcity of published literature on the use of frailty screening tools in clinical settings, particularly with individuals with IDD. The development and testing of multidimensional frailty screening tools that are easily accessible must be considered a research priority.

McCallion, McCarron, McGlinchey, Sandberg, Schoufour, Shoostari, & Temple (2019). Development of a consensus on how best to support individuals with IDD as they become frail. *Journal of Intellectual Disability Research*, 63(7), 857

University Rio Hortega Hospital, April 11, 2019 (Valladolid, Spain)

In April 2019, Lynn Martin was invited to speak to research on aging, frailty, and mental health as part of a larger gathering of the interRAI Network of Excellence in Mental Health (an international research consortium). In this presentation, information was presented on the definition, conceptualization, and measurement of frailty, with particular emphasis on how frailty has been measured in the interRAI suite of instruments. Results of research examining frailty among older adults receiving inpatient psychiatric services, and among adults with intellectual and developmental disabilities receiving home care services were reviewed. A key message was on the need to identify frailty as soon as possible to prevent, delay, and reverse frailty and associated adverse outcomes.

Martin, L., Hirdes, J.P., & Ouellette-Kuntz, H. (2019). Frailty among adults with intellectual disabilities. University Rio Hortega Hospital. April 11, 2019 (Valladolid, Spain).



Frailty, Mental Health, and Intellectual Disabilities

Lynn Martin, PhD



John P. Hirdes, PhD



Hélène Ouellette-Kuntz, PhD



April 11, 2019
University Rio Hortega Hospital, Valladolid, Spain

www.interrai.org

Submissions to peer reviewed journals

During 2019, three articles were published in peer-reviewed journals.

Lee, Ouellette-Kuntz, & Martin (2019). Applying the HC-IDD Frailty Index to Developmental Services Agency Chart Data. *Journal on Developmental Disabilities*, 24(2), 43-50.

Frailty is a common geriatric syndrome experienced earlier by adults with IDD than those without. Measurement of frailty in this population is crucial to inform care planning aimed at preventing adverse outcomes. This study sought to determine whether frailty could be measured based on information documented in developmental services agency charts and how chart-derived scores performed compared to a validated frailty measure. Records from a developmental services agency were reviewed for the presence of deficits indicated in the Home Care – Intellectual and Developmental Disabilities Frailty Index (HC-IDD FI). Only 13 of the 42 needed deficits met inclusion criteria to create a chart-derived score. In the developmental services sample (n = 170), the chart-derived score was associated with age, level of IDD, living arrangement, and hospitalization in the subsequent year, but not with sex. Poor agreement between the HC-IDD FI and scores derived from items captured in charts was observed in a sample of 106 home care recipients with IDD. Assessing frailty using developmental services agency records requires the systematic recording of changes in function to account for the dynamic nature of frailty.

Ouellette-Kuntz, Martin, Burke, McCallion, McCarron, McGlinchey, Sandberg, Schoufour, Shooshtari, & Temple (2019). How best to support individuals with IDD as they become frail: development of a consensus statement. *Journal of Applied Research in Intellectual Disabilities*, 32, 35-42.

While higher rates and earlier onset of frailty have been reported among adults with intellectual and developmental disabilities (IDD), research on how best to support these individuals is lacking. An international consultation relied on three consensus building methods: the Nominal Group Technique, an NIH consensus conference approach, and a Delphi survey. There is agreement that person-centered planning and aging in place should be guiding principles. Frailty must be considered earlier

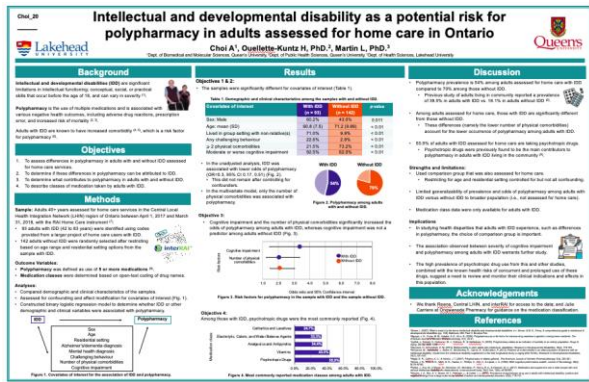
than in the general population with the recognition that improvement and maintenance are viable goals. Intersectoral collaboration is needed to coordinate assessments and actions. Safety and planning for the future are important planning considerations, as are the needs of caregivers. Ongoing research is needed. The statement offers guidance to respond to frailty among adults with IDD and fosters ongoing exchange internationally on best practice. As new evidence emerges, the statement should be revisited and revised.

Ouellette-Kuntz, H., Stankiewicz, E., McIsaac, M., & Martin, L. (2018). Improving prediction of risk of admission to long-term care or mortality among home care users with IDD. *Canadian Geriatrics Journal*, 21 (4), 303-306.

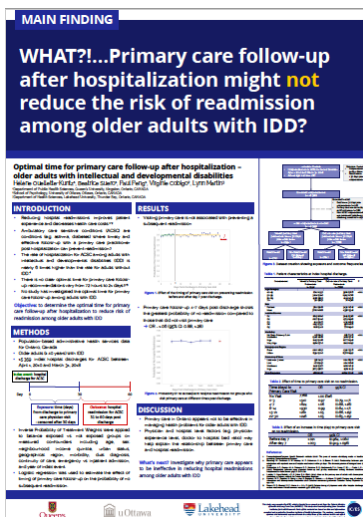
Frailty is an established predictor of admission into long-term care and mortality in the elderly population. Assessment of frailty among adults with IDD using a generic frailty marker may not be as predictive, as some lifelong disabilities associated with IDD may be interpreted as a sign of frailty. This study set out to determine if adding the Home Care-Intellectual and Developmental Disabilities Frailty Index (HC-IDD Frailty Index), developed for use in home care users with IDD, to a basic list of predictors (age, sex, rural status, and the Johns Hopkins Frailty Marker) increases the ability to predict admission to long-term care or death within one year. A retrospective cohort study was conducted using Residential Assessment Instrument for Home Care (RAI-HC) data for adult home care users with IDD who had a home care assessment between January 1, 2010 and December 31, 2013 (N = 6,169). The HC-IDD Frailty Index was found to significantly improve prediction of transitions into LTC or death by explaining an additional 5.95% of the variance in such transitions among home care users with IDD (p value < .0001). We recommend the use of the HC-IDD Frailty Index in care planning and in further research related to the effectiveness of interventions to reduce or delay adverse age-related outcomes among adults with IDD.

Posters presented

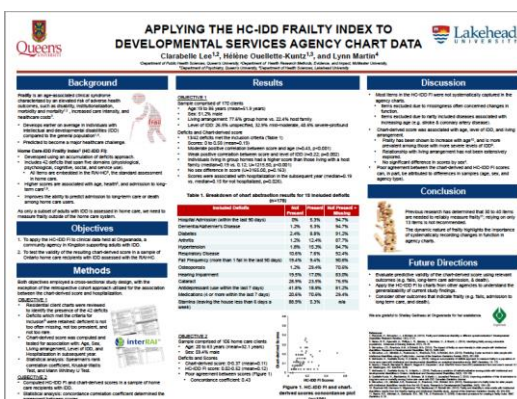
We presented our work related to frailty and polypharmacy at three different conferences.



Choi, Ouellette-Kuntz, & Martin (2019). IDD as a potential risk factor for polypharmacy in adults assessed for home care services in Ontario, Canada. OADD Research Special Interest Group Research Day, April 11, 2019 (Niagara Falls, ON).



Ouellette-Kuntz, Suero, Peng, Cobigo, & Martin (2019). Optimal time for primary care follow-up after hospitalization – older adults with intellectual and developmental disabilities (IDD). IASSID World Congress, August 6-9, 2019 (Glasgow, Scotland).



Lee, Ouellette-Kuntz, & Martin (2018). Applying the HC-IDD frailty index to developmental services agency chart data. McMaster Public Health Student Led Conference (December 5, 2018, Hamilton, ON).

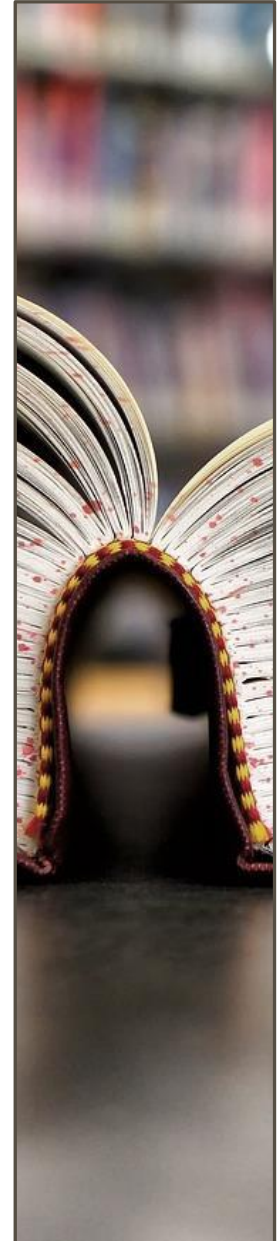
Student Involvement

Four students from Queen's University have been involved in the work featured in this report including:

- **Amy Choi**, an undergraduate student, who investigated the relationship between polypharmacy and IDD status in older adults assessed for home care.
- **Tori Barabash**, an MSc student in Epidemiology, has been assisting in the dissemination of our work by developing both videos and infographics and presenting at conferences. She also played a key role in the work on intersectoral collaboration in supporting adults with IDD who are frail
- **Beatrice Suero**, an MSc student in Biostatistics worked on an aging-related project entitled "Optimal time for primary care follow-up after hospitalization – older adults with IDD."
- **Frishta Nafeh**, a Master of Public Health student, contributed to investigating if IDD is an independent risk factor for polypharmacy.

Three students from Lakehead University have also been involved in the work featured in this report including:

- **Eve Deck**, a Master of Public Health student, worked on intersectoral collaboration to assist adults with IDD who are frail.
- **Breanna Boyd** and **Harleen Buttar**, Master of Public Health students, created workbooks for individuals with IDD who are frail and those supporting them



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