MAPS
MULTIDIMENSIONAL ASSESSMENT
OF PROVIDERS AND SYSTEMS

Lakehead
UNIVERSITY

Queen's
UNIVERSITY

Aging Project 2017/18 Update

FEBRUARY 2018

Lynn Martin, Hélène Ouellette-Kuntz, Katherine McKenzie, Mara Habash

Table of Contents

Suggested Citation:

Martin, L., Ouellette-Kuntz, H., McKenzie, K. & Habash, M. (2018). *Aging Project 2017/18 Update*. Kingston, ON: Multidimensional Assessment of Providers and Systems.

Acknowledgements

This work was supported by a grant from the Ontario Ministry of Community and Social Services. The views expressed in this report are those of the researchers and do not necessarily reflect those of the Ministry.

We gratefully acknowledge the collaboration of the Ontario Partnership on Aging and Developmental Disabilities (OPADD), a ground-breaking informal partnership of service providers in long term care and developmental disabilities (www.opadd.on.ca).

Ontario
MINISTRY OF COMMUNITY AND SOCIAL SERVICES

Ontario Partnership on
Aging & Developmental Disabilities

Project Synopsis

Our recent work revealed that adults with intellectual and developmental disabilities (IDD) experience higher rates of frailty and use of aging care services at earlier ages than the general population, and that the subset aged 65+ years is increasing. As the size of the population with IDD grows, ages, and lives longer than before, it becomes increasingly important to understand their needs – and changing needs, as well as how developmental services and health care resources can best be allocated to support them in the community.

It is important to understand the changing needs of those who age with intellectual and developmental disabilities.

This study builds on a successful program of research related to aging and IDD in Ontario, and seeks to **enhance understanding in Developmental Services by examining evolving support needs of adults as they age.**

We aimed to answer three questions:

1) Does where you live matter?
2) Once frail, always frail?
3) How quickly does one become frail?

Research Activities

Does where you live matter?

We sought to determine whether (1) home care services received by adults with IDD differed based on type of residence (i.e., group home vs. other), and (2) if after controlling for other factors, this relationship was modified by geographic region. Secondary analyses of population-level home care data were conducted using a cohort of 4,456 home care users with IDD in Ontario.

Individuals who resided in a group home differed significantly from those who lived elsewhere on all considered characteristics. They were older, had more cognitive and functional impairment, and were more frail. Type of residence was not associated with receiving nursing and therapy services but it did have an effect on receipt of home health aide and homemaking services. However, the effect varied somewhat across regions.

Where people live mattered for some, but not all services. Living in a group home or not matters more than geography.

Next steps:

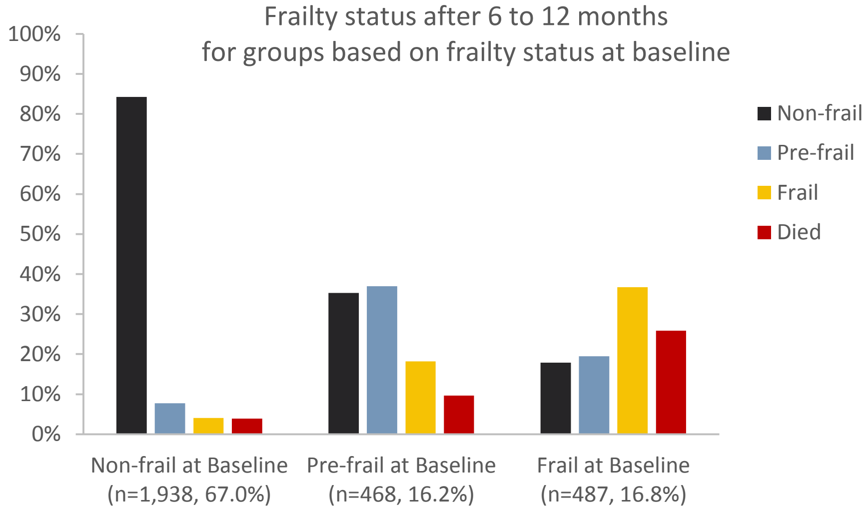
Future work is needed to better understand how sectors (home care and developmental services) come together to support adults with IDD in the community.

Once frail, always frail?

To answer this question, we described transitions in frailty status among 2,893 individuals with IDD receiving home care services in Ontario and explored the association between baseline frailty status and worsening/death over a 1-year period.

Once frail does not mean always frail. Frailty is dynamic and reversible.

The results showed different change trajectories depending on baseline frailty status. We found that non-frail individuals can become frail or die, and frail individuals can improve to the extent that they are no longer frail. Additionally, residence in a group home was significantly associated with an increase in the odds of worsening frailty status.



Next steps:

There is a need to understand the rate of deficit accumulation across frailty status.

How quickly does one become frail?

As frailty reflects accumulated deficits, another way to examine changes is to consider the rate at which individuals accumulated frailty deficits. This was done using all longitudinal data available for all recipients of home care services who have an IDD (n=5,074).

After age, baseline frailty is the strongest predictor of a high rate of deficit accumulation over time.

The results indicated that the rate of deficit accumulation was higher among those identified as pre-frail or frail at baseline, though increasing age was the strongest predictor of deficit accumulation. Presence of Down syndrome and living in a group home were also predictive of accumulation of deficits.

Next steps:

Frailty status should be monitored and care plans adjusted to address the risk of decline. Evaluation of interventions are required to guide service provision.

Source: http://www.edwinno.com/edwinno-publications/my-writings/plan-do-check-act

Knowledge User Engagement

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 closely with our primary knowledge users - the Ontario Partnership on Aging and Developmental Disabilities (OPADD), and engaged audiences more broadly through conference presentations.

Source: https://thestack.com/wp-content/uploads/2017/07/cyxtera-learning-832x333.jpg

World interRAI conference, April 2016

The team spoke about the development of a frailty measure for home care recipients with IDD at the World interRAI conference in Toronto.

Consultation with OPADD, June 2016

Lynn Martin, Hélène Ouellette-Kuntz, and Katherine McKenzie reviewed variable definitions and preliminary findings related to home care service use. This consultation guided subsequent analyses.

IASSIDD 15th World Congress, August 2016

In Melbourne, Australia, the team presented their research on home care service use by adults with IDD over time, and the need to understand changes in frailty.

IASSIDD 15TH WORLD CONGRESS
Global Partnerships: Enhancing Research, Policy and Practice
Melbourne 15-19 August 2016

Consultation with OPADD, March 2017

The researchers reviewed changes in frailty findings and discussed the need for a consensus statement. The OPADD collaborative members contributed to the development of the consensus statement through case discussions.

Scource: https://t3.ftcdn.net/jpg/01/69/07/62/240_F_169076229_ufK5kXM2nPjDc5ATyfa1zWcumzkCzlvk.jpg

Student Involvement

Three students at two universities have been involved in the work featured in this report:

- Mara Habash, an MSc student in Epidemiology at Queen's University, has been assisting in the dissemination of our work via our website, twitter and reports.
- Peyman Sharifi-Tehran and Anson Williams, Master of Public Health students at Lakehead University, contributed to the scoping review on frailty onset among community dwelling adults that informed analyses.

In addition, three students from Queen's University are participating in our ongoing work in aging and IDD:

- Elizabeth Stankiewicz (MSc. Biostatistics) and Clarabelle Lee (BSc. Life Sciences) are applying our frailty index in their research projects.
- Stephen Lam has undertaken a scoping review of primary care among older adults with IDD which will guide his MSc thesis in Epidemiology.

Scientific Activities

Submissions to peer reviewed journals

We submitted four articles to peer-reviewed journals. We have included each article's abstract and citation.

Needles in the haystack: Using open-text fields to identify persons with IDD in administrative home care data

Background: Use of administrative health data to study populations of interest is becoming more common. Identifying individuals with intellectual and developmental disabilities (IDD) in existing databases can be challenging due to inconsistent definitions and terminologies of IDD over time and across sectors, and the inability to rely on etiologies of IDD as they are frequently unknown.

Aims: To identify diagnoses related to IDD in an administrative database and create a cohort of persons with IDD.

Methods: Open-text diagnostic entries related to IDD were identified in an Ontario home care database (2003-2015) and coded as being either acceptable (e.g. Down syndrome) or ambiguous (e.g. intellectually challenged). The cognitive and functional skills of the resulting groups were compared using logistic regressions and standardized differences, and their age distributions were compared to that of the general home care population.

Results: Just under 1% of the home care population had a diagnostic entry related to IDD. Ambiguous terms were most commonly used (61%), and this group tended to be older and less impaired than the group with more acceptable terms used to describe their IDD.

Conclusions: Open-text diagnostic variables in administrative health records can be used to identify and study individuals with IDD.

Implications: Future work is needed to educate assessors on the importance of using standard, accepted terminology when recording diagnoses related to IDD.

McKenzie, K., Martin, L., & Ouellette-Kuntz, H. (2017). Needles in the haystack: using open-text fields to identify persons with intellectual and developmental disabilities in administrative home care data. *Research in Developmental Disabilities*, 69, 85-95.

Use of home care services among adults with intellectual and developmental disabilities in Ontario: Does where you live matter?

Background: Home care services are a growing segment of the health care system that support the aging population in developed nations. In Canada, adults with intellectual and developmental disabilities (IDD), living in the community, either in a group home, on their own, with a partner or family, are eligible for home care. This study sought to determine whether (1) home care services received differed based on type of residence, and (2) if after controlling for other factors, this relationship was modified by geographic region.

Methods: Secondary analyses of population-level data (2003-2015) were conducted using a cohort of 4,456 home care users with IDD in Ontario (Canada). Logistic regression informed the relationship between residence, region, and home care services used.

Results: Home care users with IDD living in group homes were older, had more cognitive and functional impairment, and were more frail. Controlling for these, type of residence was not associated with receiving nursing and therapy services, but it interacted with age and frailty in predicting receipt of meal services. Region modified the effect of residence on receipt of home health aide and homemaking.

Discussion: Where people live mattered for some, but not all services. While similar use of home care services was observed across regions, very different patterns emerged for those living in group homes. Future work is needed to better understand how sectors (home care and developmental/social services) come together to support adults with IDD in the community.

Martin, L., Ouellette-Kuntz, H., & McKenzie, K. (2018). Use of home care services among adults with intellectual and developmental disabilities in Ontario : Does where you live matter? *Research and Practice in Intellectual and Developmental Disabilities.* DOI : 10.1080/23297018.2018.1443023

Once frail, always frail? Frailty transitions in home care users with intellectual and developmental disabilities

Aim: Frailty is understood as a dynamic non-linear process, and used to indicate age-related decline. Recent work has shown that adults with intellectual and developmental disabilities experience higher rates of frailty at much earlier ages than the general population. The present study describes transitions in frailty status (i.e. non-frail, pre-frail, frail) over 1 year, and explores the association between baseline frailty status and worsening/death over time.

Methods: Results are based on secondary analysis of 2893 individuals with intellectual and developmental disabilities receiving community-based home care services in Ontario (Canada). Frailty status is based on a validated 42-item frailty index (FI); where FI ≤0.21 indicates non-frail, 0.21 < FI ≤ 0.3 indicates pre-frail and FI >0.30 indicates frail. Baseline characteristics of frailty groups at baseline were compared using the χ2-test/analysis of variance. Relative risk of worsening/dying was calculated using a modified Poisson regression model.

Results: Initially, 67.0% of participants were non-frail, 16.2% were pre-frail and 16.8% were frail. Of those nonfrail at baseline, 84.3% remained non-frail, 11.8% worsened and 3.9% died. Among those initially pre-frail, 37.0% remained stable, 35.3% improved, 18.2% worsened and 9.6% died. Although similar proportions of frail individuals improved (37.4%) or remained stable (36.8%), 25.9% had died. After controlling for other factors, being pre-frail at baseline was associated with an increase in the risk of worsening or death (RR 1.24, 95% CI 1.04–1.49).

Conclusions: While many experience worsening of frailty status, stability and improvement are viable goals of care. Future research should examine the rate at which non-frail, pre-frail and frail individuals accumulate deficits, as well as the impact of home care services on frailty.

Martin, L., McKenzie, K., & Ouellette-Kuntz, H. (2017). Once frail, always frail? Frailty transitions in home care users with intellectual and developmental disabilities. *Geriatrics and Gerontology International.* DOI: 10.1111/ggi.13214

Rate of deficit accumulation in home care users with intellectual and developmental disabilities

Purpose: To identify factors associated with the rate of deficit accumulation in a population of adults with intellectual and developmental disabilities.

Methods: A longitudinal analysis of administratively-held clinical data collected at routine home care assessments across Ontario (Canada) using the Resident Assessment Instrument for Home Care (RAI-HC) was conducted using a cohort comprised of 5,074 adults with IDD 18 to 99 years of age who had at least two home care assessments between April 1st, 2003 and March 31st, 2015. Rates of deficit accumulate were calculated across variables of interest. Incidence rate ratios and 95% confidence intervals are presented. Negative binomial regression models using a generalized estimating equation (GEE) approach were developed.

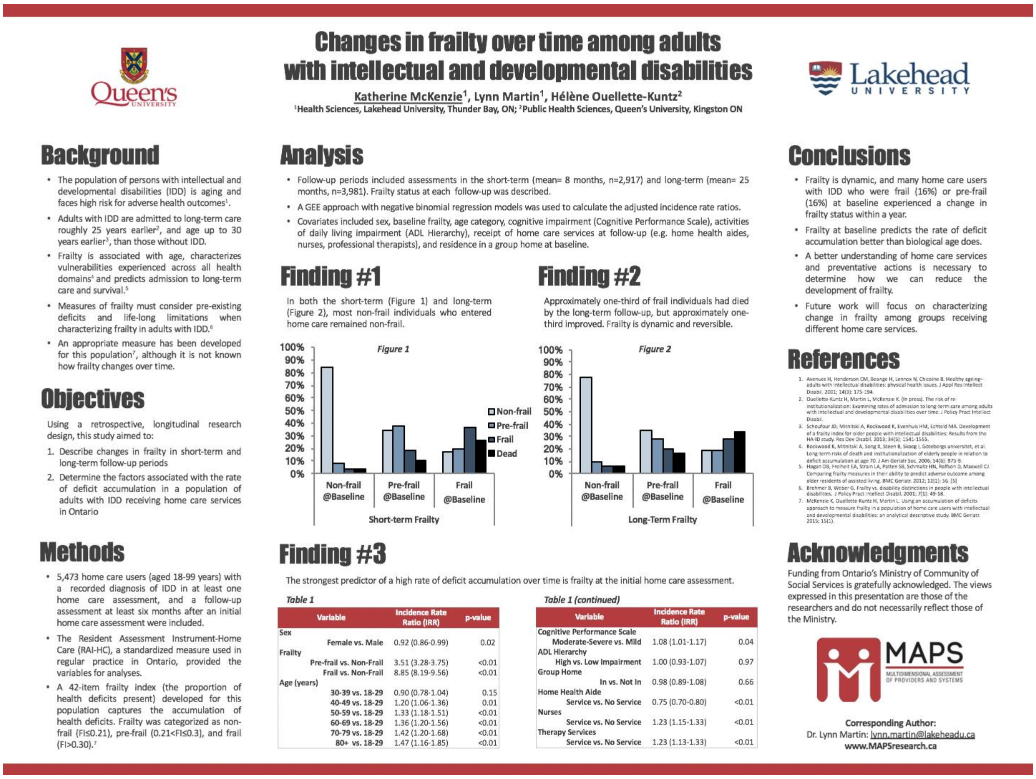
Results: Increasing age, Down syndrome and living in a group home were significant predictors of deficit accumulation. Rates of deficit accumulation tended to be higher among pre-frail and frail individuals however, impaired cognition and impairment in activities of daily living were associated with slower deficit accumulation. The relationship between provision of nursing and therapy services and deficit accumulation is unclear.

Conclusions: Frailty should be monitored among adults with IDD starting at age 40, those with Down syndrome, and those who live in group homes.

Ouellette-Kuntz, H., Martin, L., & McKenzie, K. (2018). Rate of deficit accumulation in home care users with intellectual and developmental disabilities. *Annals of Epidemiology*. DOI : 10.1016/j.annepidem.2018.01.010

Other scientific activity

We presented the following poster at the Canadian Association on Gerontology Conference.



Changes in frailty over time among adults with intellectual and developmental disabilities

Katherine McKenzie[1], Lynn Martin[1], Hélène Ouellette-Kuntz[2]
[1]Health Sciences, Lakehead University, Thunder Bay, ON; [2]Public Health Sciences, Queen's University, Kingston ON

Background

- The population of persons with intellectual and developmental disabilities (IDD) is aging and faces high risk for adverse health outcomes[1].
- Adults with IDD are admitted to long-term care roughly 25 years earlier[2], and age up to 30 years earlier[3], than those without IDD.
- Frailty is associated with age, characterizes vulnerabilities experienced across all health domains[4] and predicts admission to long-term care and survival.[5]
- Measures of frailty must consider pre-existing deficits and life-long limitations when characterizing frailty in adults with IDD.[6]
- An appropriate measure has been developed for this population[7], although it is not known how frailty changes over time.

Objectives

Using a retrospective, longitudinal research design, this study aimed to:

1. Describe changes in frailty in short-term and long-term follow-up periods
2. Determine the factors associated with the rate of deficit accumulation in a population of adults with IDD receiving home care services in Ontario

Methods

- 5,473 home care users (aged 18-99 years) with a recorded diagnosis of IDD in at least one home care assessment, and a follow-up assessment at least six months after an initial home care assessment were included.
- The Resident Assessment Instrument-Home Care (RAI-HC), a standardized measure used in regular practice in Ontario, provided the variables for analyses.
- A 42-item frailty index (the proportion of health deficits present) developed for this population captures the accumulation of health deficits. Frailty was categorized as non-frail (FI≤0.21), pre-frail (0.21<FI≤0.3), and frail (FI>0.30).[7]

Analysis

- Follow-up periods included assessments in the short-term (mean= 8 months, n=2,917) and long-term (mean= 25 months, n=3,981). Frailty status at each follow-up was described.
- A GEE approach with negative binomial regression models was used to calculate the adjusted incidence rate ratios.
- Covariates included sex, baseline frailty, age category, cognitive impairment (Cognitive Performance Scale), activities of daily living impairment (ADL Hierarchy), receipt of home care services at follow-up (e.g. home health aides, nurses, professional therapists), and residence in a group home at baseline.

Finding #1

In both the short-term (Figure 1) and long-term (Figure 2), most non-frail individuals who entered home care remained non-frail.

Finding #2

Approximately one-third of frail individuals had died by the long-term follow-up, but approximately one-third improved. Frailty is dynamic and reversible.

Figure 1

Figure 2

Finding #3

The strongest predictor of a high rate of deficit accumulation over time is frailty at the initial home care assessment.

Table 1

Variable	Incidence Rate Ratio (IRR)	p-value
Sex		
Female vs. Male	0.92 (0.86-0.99)	0.02
Frailty		
Pre-frail vs. Non-Frail	3.51 (3.28-3.75)	<0.01
Frail vs. Non-Frail	8.85 (8.19-9.56)	<0.01
Age (years)		
30-39 vs. 18-29	0.90 (0.78-1.04)	0.15
40-49 vs. 18-29	1.20 (1.06-1.36)	0.01
50-59 vs. 18-29	1.33 (1.18-1.51)	<0.01
60-69 vs. 18-29	1.36 (1.20-1.56)	<0.01
70-79 vs. 18-29	1.42 (1.20-1.68)	<0.01
80+ vs. 18-29	1.47 (1.16-1.85)	<0.01

Table 1 (continued)

Variable	Incidence Rate Ratio (IRR)	p-value
Cognitive Performance Scale		
Moderate-Severe vs. Mild	1.08 (1.01-1.17)	0.04
ADL Hierarchy		
High vs. Low Impairment	1.00 (0.93-1.07)	0.97
Group Home		
In vs. Not In	0.98 (0.89-1.08)	0.66
Home Health Aide		
Service vs. No Service	0.75 (0.70-0.80)	<0.01
Nurses		
Service vs. No Service	1.23 (1.15-1.33)	<0.01
Therapy Services		
Service vs. No Service	1.23 (1.13-1.33)	<0.01

Conclusions

- Frailty is dynamic, and many home care users with IDD who were frail (16%) or pre-frail (16%) at baseline experienced a change in frailty status within a year.
- Frailty at baseline predicts the rate of deficit accumulation better than biological age does.
- A better understanding of home care services and preventative actions is necessary to determine how we can reduce the development of frailty.
- Future work will focus on characterizing change in frailty among groups receiving different home care services.

References

1. Avenues H, Henderson CM, Beange H, Lennox N, Chicoine B. Healthy ageing–adults with intellectual disabilities: physical health issues. J Appl Res Intellect Disabil. 2001; 14(3): 175-194.
2. Ouellette-Kuntz H, Martin L, McKenzie K. (In press). The risk of re-institutionalization: Examining rates of admission to long-term care among adults with intellectual and developmental disabilities over time. J Policy Pract Intellect Disabil.
3. Schoufour JD, Mitnitski A, Rockwood K, Evenhuis HM, Echteld MA. Development of a frailty index for older people with intellectual disabilities: Results from the HA-ID study. Res Dev Disabil. 2013; 34(5): 1541-1555.
4. Rockwood K, Mitnitski A, Song X, Steen B, Skoog I, Göteborgs universitet, et al. Long-term risks of death and institutionalization of elderly people in relation to deficit accumulation at age 70. J Am Geriatr Soc. 2006; 54(6): 975-9.
5. Hogan DB, Freiheit EA, Strain LA, Patten SB, Schmaltz HN, Rolfson D, Maxwell CJ. Comparing frailty measures in their ability to predict adverse outcome among older residents of assisted living. BMC Geriatr. 2012; 12(1): 56. [5]
6. Brehmer B, Weber G. Frailty vs. disability distinctions in people with intellectual disabilities. J Policy Pract Intellect Disabil. 2001; 7(1): 49-58.
7. McKenzie K, Ouellette-Kuntz H, Martin L. Using an accumulation of deficits approach to measure frailty in a population of home care users with intellectual and developmental disabilities: an analytical descriptive study. BMC Geriatr. 2015; 15(1).

Acknowledgments

Funding from Ontario's Ministry of Community of Social Services is gratefully acknowledged. The views expressed in this presentation are those of the researchers and do not necessarily reflect those of the Ministry.

MAPS
MULTIDIMENSIONAL ASSESSMENT OF PROVIDERS AND SYSTEMS

Corresponding Author:
Dr. Lynn Martin: lynn.martin@lakeheadu.ca
www.MAPSresearch.ca

McKenzie, K., Martin, L., & Ouellette-Kuntz, H. (2016, October). Changes in frailty over time among adults with intellectual and developmental disabilities. Canadian Association on Gerontology Conference. Montreal, Ontario, Canada.

Author Information

Lynn Martin
Associate Professor
Tel (807) 766-7245
Fax (807) 766-7225
lynn.martin@lakeheadu.ca

Hélène Ouellette-Kuntz
Professor
Tel (613) 548-4417 x. 1198
Fax (613) 548-8135
helene.kuntz@queensu.ca

Katherine McKenzie
Project Manager
kmckenzi@lakeheadu.ca

Mara Habash
Research Assistant
mara.habash@queensu.ca

MAPS
MULTIDIMENSIONAL ASSESSMENT
OF PROVIDERS AND SYSTEMS

Multidimensional Assessment of Providers and Systems (MAPS)
Ongwanada Resource Centre
191 Portsmouth Avenue
Kingston, Ontario, Canada K7M 8A6
mapsresearch.ca