



MAPS

MULTIDIMENSIONAL ASSESSMENT
OF PROVIDERS AND SYSTEMS



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Aging Project 2016 Update **DECEMBER 2016**

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**Canadian
Frailty
Network**



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Project Synopsis

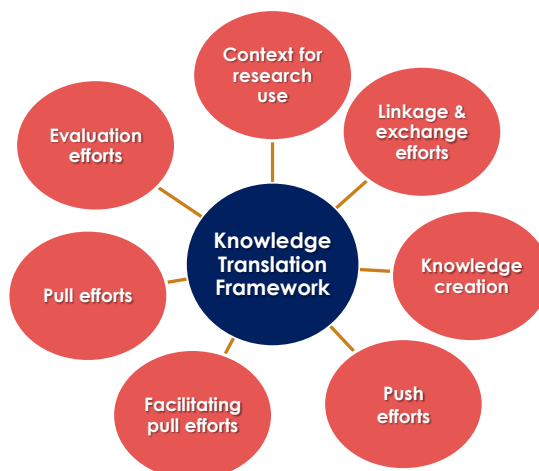
Adults with intellectual and developmental disabilities (IDD) face unique aging challenges, and early identification of frailty may help to ensure timely and appropriate supports. This study aimed to improve community care and clinical outcomes of adults with IDD who are frail or at risk of frailty by informing the development and use of a tool to measure frailty in this population.

The Canadian Frailty Network-funded project aimed to answer the following questions:

- (1) What does the literature say about frailty and IDD?
- (2) What can we learn from other jurisdictions about implementing a frailty measure for persons with IDD in Ontario?

The World Health Organization (WHO) Knowledge Translation Framework for Ageing and Health guided our approach to understanding uptake of frailty measures into policy and practice.

It is important to understand why and how to measure frailty in adults with IDD in practice.



Research Activities

Objective 1: What does the literature say about frailty and IDD?

A scoping review of the literature related to frailty among aging adults with IDD was conducted. Seventeen publications of original research published between 2000 and December 31st, 2015 were retrieved. Only four groups have been involved in this work around the world: one in the Netherlands, one in Austria, one in Taiwan and our team in Canada.

Who is most likely to be frail?

Several studies viewed frailty as an outcome of interest and reported associations with many factors such as age, gender and level of intellectual disability. The presence of dementia, Down syndrome, mental illness or addiction, and loss of skeletal muscle mass and strength were also positively associated with frailty.

What can frailty tell us about an individual?

The research reviewed indicated that among adults with IDD, frailty reduces survival in the community, is correlated with a decrease in functioning at follow-up, and increases in future medication use and in care intensity, including hospitalization and long-term care admission.

Frailty is associated with many negative outcomes in adults with IDD.

Next Steps

Considering how frailty measures could be integrated in assessment and care planning and understanding how best to use knowledge of frailty at the population level for policy decisions are important next steps.

Objective 2: What can we learn from other jurisdictions about implementing a frailty measure for persons with IDD in Ontario?

The second component involved key informant interviews to determine how frailty measures have been used to assess and monitor frailty among older adults with IDD.

The interviews, based on the seven elements of the World Health Organization Knowledge Translation Framework for Ageing and Health (see page 2), set out to understand the willingness to learn about aging among persons with IDD. Two individuals from each of the two Europe-based research teams who have published research on measures of frailty in populations with IDD were interviewed.

We learned that:

- to date, measures of frailty have not been used to support policy-making;
- to be implemented in practice, a frailty measure must be brief, relevant and it must inform care decision; and
- linkages between frailty researchers and practitioners and policy-makers are key to successful implementation of measures developed.

"The more extensive [our] knowledge of what has been done, the greater will be [our] power of knowing what to do."

*Benjamin
Disraeli*



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 (Reena and the Ontario Partnership on Aging & Developmental Disabilities represented by Sandy Stemp) and engaged audiences more broadly through webinars, conferences and the Canadian Frailty Network (CFN)'s website.

Watch the webinar:

mapsresearch.ca/resources/videos/

End of Project Webinar for CFN, February 2016

The team provided an interactive webinar on implementing a measure for older adults with IDD.

Global Partnerships in Intellectual Disability Health: Enhancing research, policy and practice, August 2016

Dr. H el ene Ouellette-Kuntz was invited to Sydney, Australia to share work on aging and IDD with service providers, policy makers and researchers.

Central Region Partnership on Aging and Developmental Disabilities Conference, October 2016

The team was invited to discuss complexities of aging in intellectual disabilities at an event sponsored by the Central West Network of Specialized Care, Homewood health Centre and Waterloo/Wellington BSO.

Other

The results of our work were summarized for key stakeholder groups: policy makers, families, and researchers. These are posted on the CFN's website.

More information at:

<http://aci.mediahousingplus.com/intellectual-disability-health-symposium/view/prof-helene-ouellette-kuntz>

<http://www.cfn-nce.ca/research-evidence/funded-research/fra2015-a-03-ouellette-kuntz>

Scientific Activities

Submissions to peer reviewed journals

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

Frailty and Intellectual and Developmental Disabilities: a Scoping Review

Background: Individuals with intellectual and developmental disabilities (IDD) are both living longer than in previous generations and experiencing premature aging. Improved understanding of frailty in this aging population may inform community supports and avoid negative outcomes.

Methods: The objective of this study was to review the literature on frailty and IDD and determine areas for future research and application. The methodological framework for a scoping review as developed by H. Arksey and L. O'Malley was applied to identify and select original studies published since 2000.

Results: Seventeen studies were identified; these were based on the work of researchers from four research programs. The studies utilized six measures of frailty, including two frailty indices, the VFQ-ID(-R), the frailty phenotype, and the frailty marker. Frailty was equally studied as an outcome and as predictor for other outcomes (e.g., mobility, falls, care intensity, institutionalization, and survival).

Conclusions: There is evidence of a growing interest in the measurement of frailty in aging adults with IDD. As in the general population, frailty in this group is associated with many negative outcomes. While a few measures have emerged, more work is required to replicate results, validate tools, and test the feasibility of applying frailty measures in practice and to inform policy.

McKenzie, K., Martin, L., & Ouellette-Kuntz, H. (2016) Frailty and Intellectual and Developmental Disabilities: a Scoping Review, Canadian Geriatrics Journal, 19, 103-112. doi: <http://dx.doi.org/10.5770/cgj.19.225>


Understanding implementations of frailty measures among adults with intellectual and developmental disabilities

Interest in frailty measures to inform clinical practice and policy decisions has been growing in recent years. Outside of Canada, two research teams in the field of intellectual and developmental disabilities (IDD) have developed frailty measures, although it is not known how these measures could be applied in practice. Key informants from each research team were interviewed about knowledge translation experiences. The transcripts were analyzed using the World Health Organization's Knowledge Translation Framework for Ageing and Health. Neither frailty measure has yet been used to support policy-making. To be implemented in practice, a frailty measure must be brief, relevant, and inform care decisions. The interviews revealed actions that should be taken prior to knowledge, including ensuring that the frailty measures are valid and have a clear purpose, and collaborating with appropriate knowledge users. Linkages between frailty researchers and practitioners and policy-makers are key to successful implementation of measures developed. Lessons from this study may be used to implement frailty measures in a Canadian population of older adults with intellectual and developmental disabilities.

McKenzie, K., Martin, L., & Ouellette-Kuntz, H. (2016). Understanding implementations of frailty measures among adults with intellectual and developmental disabilities. *Journal on Developmental Disabilities*, 22(2). See www.oadd.org/index.php?page=142

Poster presentations at conferences


We presented a poster at two conferences.



Examining how a frailty index can be used in the field of IDD

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Background

- A growing number of adults with intellectual and developmental disabilities (IDD) are experiencing old age, and many who are frail face an increased risk of negative health outcomes¹.
- For example, adults with IDD are admitted to long-term care roughly 25 years earlier than those without IDD², and have a higher use of health care services³.
- The need for an appropriate measure of frailty is recognized⁴ and a few measures have recently been developed^{5,6}.
- There is a limited discussion in the literature about how best to integrate such frailty measures in care planning, service planning and policy development.
- A scoping review would reveal the present research of frailty in this population and current practices of frailty implementation.

Objectives

The overall goal is to improve community care and clinical outcomes of Canadians with IDD who are frail by developing procedures for identifying them and prompting appropriate action on the part of providers, planners and policy makers.

Methods

Part 1: Scoping Review

Following Arksey & O'Malley's (2005) framework⁷, a scoping review of the literature was conducted to explore, summarize, and disseminate the knowledge of frailty in adults with IDD (Fig. 1).

Figure 1

Identify the research question
What factors have been identified as contributing to frailty/increased health vulnerability among adults with intellectual and developmental disabilities as they age?

Identify all relevant studies
Articles located by conducting an electronic search of the literature. The following databases were included: an initial search returned three gold standard articles: Medline, PsycINFO, EMBASE, CINAHL, Cochrane Library, TRIP Reviews, and Joanna Briggs Institute. The search was limited to articles published after 2000.

Study Selection
For a full-text review, articles' abstracts must have:
1) described individuals with IDD;
2) included adults ≥ 50 years of age; and
3) included a measure of frailty. Agreement of at least two members determined final inclusion.

Charting the data
A tracking and review form summarized the articles, including study populations, methods, key results, and discussion points.

Methods (Continued)

Part 2: Key Informant Interviews

- The second component will involve key informant interviews to determine how frailty measures have been used to assess and monitor frailty among older adults with IDD in various jurisdictions.
- The interviews, based on the WHO Ageing & Health Knowledge Translation Framework⁸ (Fig. 2), will seek to understand the willingness to learn about aging among persons with IDD, the presence of formal and informal partnerships and the availability of resources for implementing and monitoring of evidence-informed policies.




Figure 2

Key Findings

- Most studies (n=15 of 16) were published in 2009 or later:

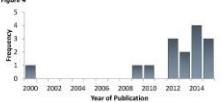


Figure 4

- Most studies focused on frailty as a predictor of outcomes such as care intensity, sarcopenia, fractures, falls, increased medication use, and mortality. Other studies found associations between frailty and risk factors, like poor mobility and functional status.

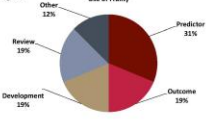


Figure 5

- While none of the studies explored the use of frailty measures in practice, many discussed the possibilities of using frailty measures to identify individuals at risk of decline who could benefit from early interventions.
- A valid frailty measure was also thought to be useful for evaluating interventions, and describing individuals over time.
- Some studies indicated the need to collaborate with general health care professionals as well as practitioners who work specifically with adults with IDD before implementing a frailty tool.

Results

Part 1: Scoping Review

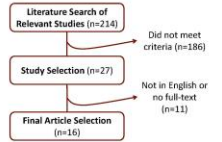


Figure 3

Four measures of frailty were identified in 16 articles (Fig. 3):

- Vienna Frailty Questionnaire for persons with Intellectual Disabilities- Revised (VFQ-ID-R)⁹
- Healthy Aging and Intellectual Disability (HA-ID) Frailty Index⁴
- HA-ID frailty phenotype¹⁰
- Unspecified measure¹¹

Conclusion

- Future research should continue to develop and validate appropriate measures of frailty.
- Work is also needed to investigate the feasibility and effectiveness of using frailty measures in practice.

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McKenzie, K., Martin, L. & Ouellette-Kuntz, H. (2015, September). Examining how a frailty index can be used in the field of IDD. Poster presented at:

- International Association for the Scientific Study of Intellectual and Developmental Disabilities Profound Intellectual and Multiple Disabilities Special Interest Research Group's Roundtable, Vasteras, Sweden.
- 3rd Annual TVN Conference Improving care for frail elderly Canadians, Toronto, Ontario, Canada.

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