



Health Care Access Research  
and Developmental Disabilities



Lakehead  
UNIVERSITY



# Aging Project Final Report

**MARCH 2016**

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## Acknowledgements

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### **Suggested Citation:**

Ouellette-Kuntz, H., Martin, L., & McKenzie, K. (2016). *Aging Project Final Report*. Toronto, ON: Health Care Access Research and Developmental Disabilities Program.

## Project Synopsis

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Being able to age at home is important for individuals with developmental disabilities (DD). It makes a difference to their caregivers too. But most health care services target the 'average consumer' and adults with DD have different needs. Also, the number of adults with DD who require aging care is likely much higher than the number of seniors with DD (i.e., aged 65 years or more), as individuals with DD tend to age prematurely.

In short, there is an urgent need for more knowledge about the health and health care of those with DD who are aging.

The H-CARDD Aging project had three objectives:

- (1) Determine the age at which the health care needs of adults with DD resemble the needs of seniors without DD;
- (2) Determine the rates of admission to home care services and how these services are used;
- (3) Determine the rates and predictors of admission to long-term care for adults with DD.

This work aligned with Ontario's Aging at Home Strategy (2010), which enables people to remain healthy and live independently in their own homes.

*How old is old when someone has a developmental disability?*

## Research Activities

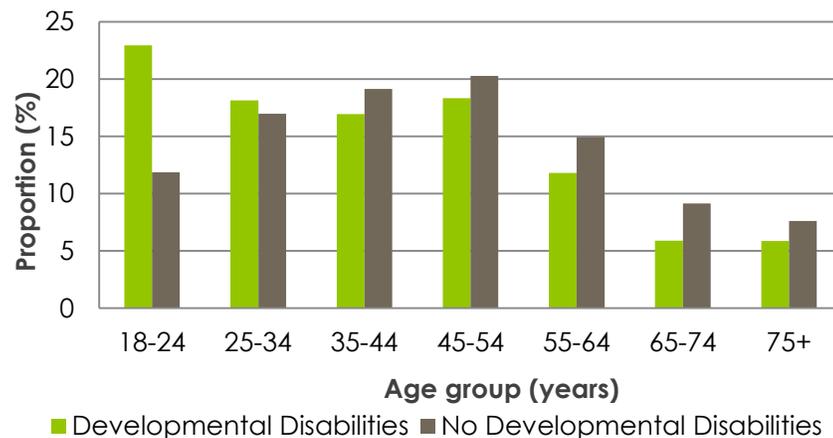
### Objective 1: The age at which the health care needs of adults with DD resemble the needs of seniors without DD

*We recommend lowering the eligibility requirements for adults with DD accessing geriatric and aging care services.*

#### Population Aging

The cohort of adults with DD was younger than the comparison cohort, and had a significantly greater proportion in the youngest age group (Figure 1).

**Figure 1:** Age distribution of adults in 2009/10



Three methods were used to project the size of the aging population with DD. Projections of the number of adults with DD 45 to 84 years of age over a 10-year period vary depending on the method used. One method suggests a moderate increase (20.5%) while the second method suggests a small increase (4.1% to 8.4%). It was also projected that the number of adults with DD 65 to 84 years of age will increase by 17 to 21%. The results highlight the need for critical examination of the population growth projection methods, and for better age and mortality statistics specific to persons with DD in particular, in order to inform system-level planning for an aging population with DD.

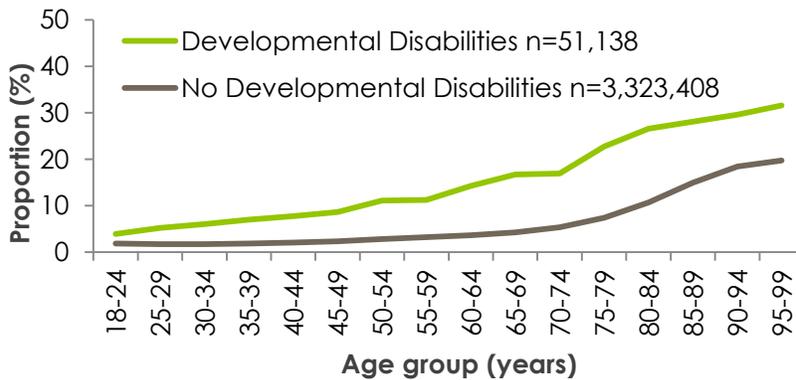
**Frailty**

In Ontario, the diagnosis-based Johns Hopkins measure of frailty is often used to inform resource needs. Using this marker, we found that the overall occurrence of frailty was three times higher among adults with DD (9%) than among those without DD (3%). In both groups, being female and having a mental illness or addiction was associated with higher occurrence of frailty. Frailty was also associated with higher use of home care and long-term care.

The age at which frailty appeared differed between groups. The proportion of adults with DD 50-54 years of age who were frail (3.9%) was comparable to that among 80-84 year olds without DD (3.6%). As such, frailty occurs much earlier among adults with DD (Figure 2).

*We recommend assessing frailty to inform support needs.*

**Figure 2:** Proportion of adults with frailty in 2009-10



The extent to which these patterns were observed using a measure of frailty that takes into account lifelong impairment and change in status was investigated using a new measure of frailty developed based on items from the Resident Assessment Instrument- Home Care (RAI-HC). Using this measure, roughly a quarter of home care users with DD were frail. Also, frailty based on this measure was significantly associated with admission to long-term care among those with DD.

## Objective 2: Rates of admission and use of home care services among adults with DD

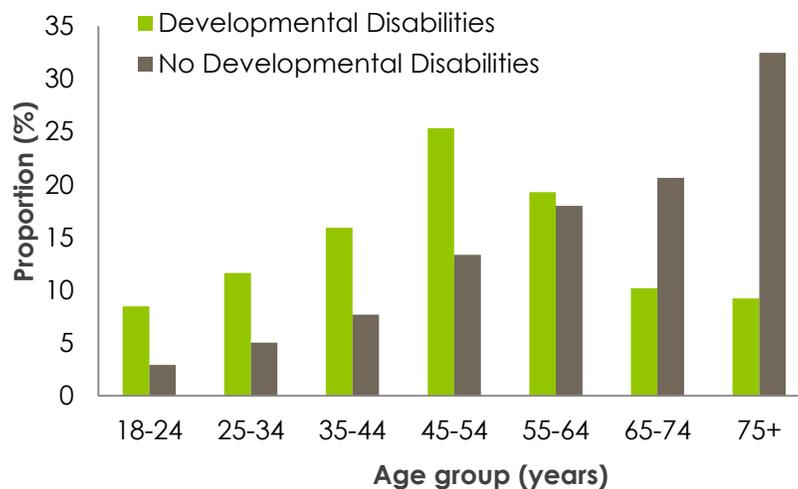
### Rates of admission to home care

*We recommend monitoring the use of home care services by adults with DD across the province.*

Between 2009 and 2013, annual rates of admission to home care were two to three times higher among adults with DD. However, a different pattern in admission was identified for adults with and without DD. Specifically, admission rates among persons with DD slightly decreased and then returned to initial levels by the end of the 5-year period, whereas a steady (though small) increase was observed in the cohort without DD.

While admission to home care increases with age in both groups, it was higher and observed at much younger ages in those with DD (Figure 3).

**Figure 3:** Ages of adults with and without DD (in 2009) admitted to Home Care between 2009 and 2013



The use of home care also varied across the province (by Local Health Integration Network), between 2.4% and 14.1% of residents with DD being admitted to home care.

### Home care services

Analyses revealed a similar pattern of home care service use by persons with and without DD (see Table 1).

**Table 1.** Home care services used among home care users with and without DD in Ontario (2009-2014)

Home care services	Adults with DD <sup>1</sup> %	Adults without DD <sup>2</sup> %
Special procedures	54.2%	56.4%
Programs	37.2%	35.7%
Therapies	30.0%	38.0%
Respiratory treatments	6.6%	8.4%
Other treatments	16.3%	19.9%
Home health aides	17.8%	22.0%
Homemaking	15.9%	17.4%
Meals	3.8%	3.0%

<sup>1</sup>n=5,165; <sup>2</sup>n=118,420

In both groups, approximately half had received special procedures (e.g., nurse monitoring, skin treatment, special diet), and approximately one third had received various programs (e.g., day centre, day hospital, hospice care, respite care) and therapies (e.g., exercise, occupational, physical). A relatively small proportion received respiratory treatments (e.g., oxygen, respirator), and other types of health care (e.g., chemotherapy, dialysis, ostomy care). Home care services that focused on maintaining independence (i.e., home health aides, homemaking, and meals) were also similar between the two groups.

### Objective 3: Rates and predictors of admission to long-term care among home care users with DD

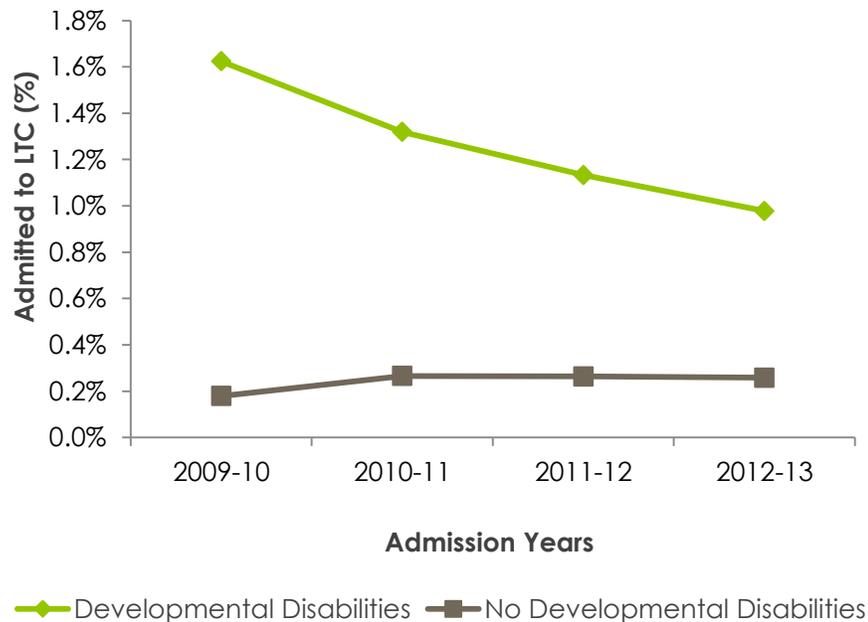
#### Rates of admission to long-term care

*We recommend monitoring the trend of admissions to long-term care among adults with DD.*

Between April 1, 2009 and March 31, 2013, 4.5% of adults with DD were newly admitted to long-term care. This proportion was much greater than for adults without DD (0.9%).

Examination of rates of admission to long-term care between 2009 and 2013 show that overall, rates of admission were three to nine times higher among persons with DD (see Figure 4). A different pattern in admission rates over time was also evident between the two groups. Specifically, admission rates among persons with DD slightly decrease over the 4-year period, whereas there was an initial increase after the first year observed in the cohort without DD that then remained stable.

**Figure 4:** Proportion of adults with and without DD admitted to long-term care between in 2009 and 2013

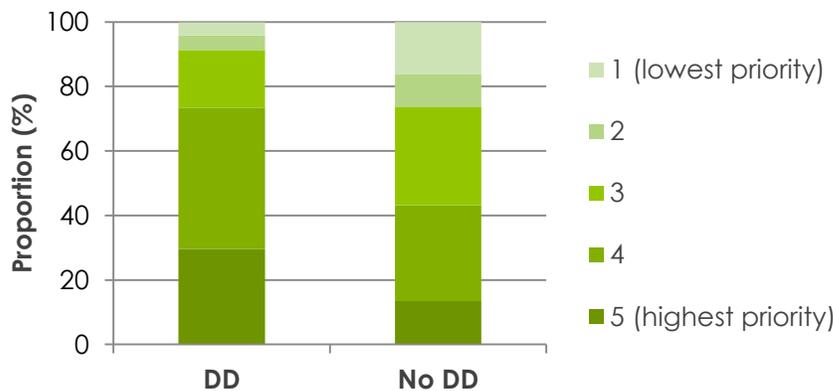


**Predictors of admission to long-term care**

In Ontario home care settings, the Method for Assigning Priority Levels (MAPLe) algorithm is often used to identify individuals likely to require long-term care. Those with DD are three times more likely to receive the highest prioritization level on the MAPLe compared to those without DD (Figure 5), despite being younger (mean age of 55 ± 18 years, vs. 77 ± 12 years, among those without DD). The MAPLe is highly reliant on static measurement of activities of daily living and level of cognitive functioning and does not account for the unique needs of individuals whose disabilities onset in childhood. As such, adults with DD may be unnecessarily prioritized for long-term care rather than supported in the community.

*We recommend ensuring that measures used to plan individual services meet the unique needs of adults with DD.*

**Figure 5:** MAPLe scores among adult home care users



We found that 12.6% of adults with DD were admitted to long-term care within 90 days of admission to home care, compared to 9.7% of adults without DD – making them 31.5% more likely to be admitted. This remained true after controlling for age, sex, mental illness and addiction, pain, performance of activities of daily living, cognition, as well as receipt of formal home care services (nursing, health aid, therapies), use of psychotropic medications, hospital admissions in the previous 90 days, and informal support (relationship, number of hours).



## Knowledge User Engagement

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Engaging with knowledge users throughout the research process is important to produce results that are likely to be both directly relevant to and employed by knowledge users.

### Our knowledge users

- Sandy Stemp (Reena/Ontario Partnership on Aging & Developmental Disabilities)
- Bill Sullivan (Family Physician)
- Robert Francis (Ministry of Health and Long-Term Care)
- Rachel Ortiz (Ministry of Community and Social Services)
- Suzanne Rowe Knight (Ministry of Community and Social Services)

### Meetings

Six meetings were held with our knowledge users, on:

- June 10, 2013
- December 6, 2013
- September 25, 2014
- January 29, 2015
- October 26, 2015
- February 23, 2016 (H-CARDD Provincial Event)

## Virtual Town Hall Webinar, February 2015

On February 19, 2015, we hosted a Canada-wide interactive virtual Town Hall. We met via webinar with over 200 providers, managers, and decision-makers in the fields of health and developmental disabilities to share findings from our age-related work among adults with developmental disabilities.

From this session, we found that there was a consensus that the system (including health and developmental services) is not ready for an increase in the aging population of adults with developmental disabilities. There is need for system reform, better collaboration, and integration- particularly around the issue of admission to long-term care.

Through this engagement with knowledge users, the research team identified five (5) priority areas related to improving health and health care among aging adults with developmental disabilities (DD):

- (1) Better and more cross-sector expertise;
- (2) Greater investment in developmental services;
- (3) Support for informal carers/families;
- (4) System organization (or re-organization); and
- (5) Long-term care designed to meet the needs of adults with DD.

Ouellette-Kuntz, H., Martin, L. & McKenzie, K. (2015, February). [Aging and Developmental Disabilities: Frailty, Home Care and Long-term Care](#). [Virtual TownHall]

Watch the  
webinar:

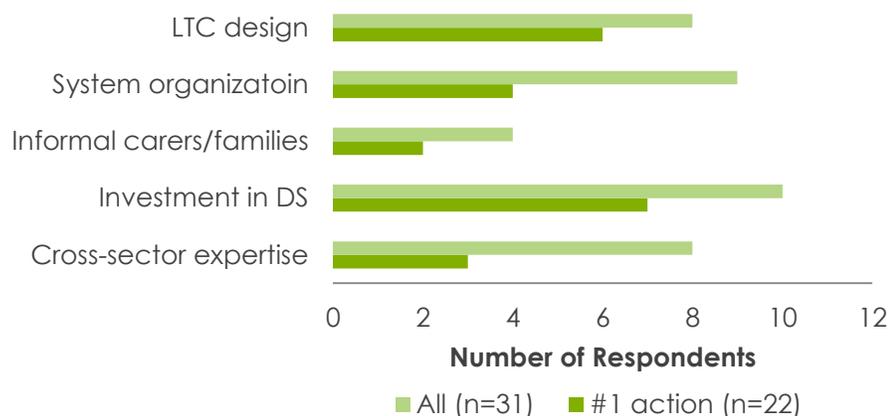
<https://www.porticowork.ca/web/hcardd/aging/town-hall-aging>

### Health & Wellbeing Conference, October 2015

We met with a group of over 30 knowledge users at the 2015 Health and Wellbeing in Developmental Disabilities (H&WB) conference in Toronto, ON. We presented the five priority areas to this group, and asked each individual to indicate which he/she thought was *the* most important action to take. In this group, 22 individuals (71%) prioritized a single action, whereas 9 individuals believed that a combination of actions was most appropriate.

Figure 6 shows the results of the prioritization exercise. The need for greater investment in the developmental services sector was the highest ranked priority area (on its own and when combined with other priority areas), followed by designing long-term care to better meet the needs of individuals with DD. The need for system organization (or re-organization), and better/more cross-sector expertise were also often ranked as important, but largely in combination with another action. Support for informal carers/families was least often ranked as the top priority for action.

**Figure 6:** Results of action prioritization at H&WB conference

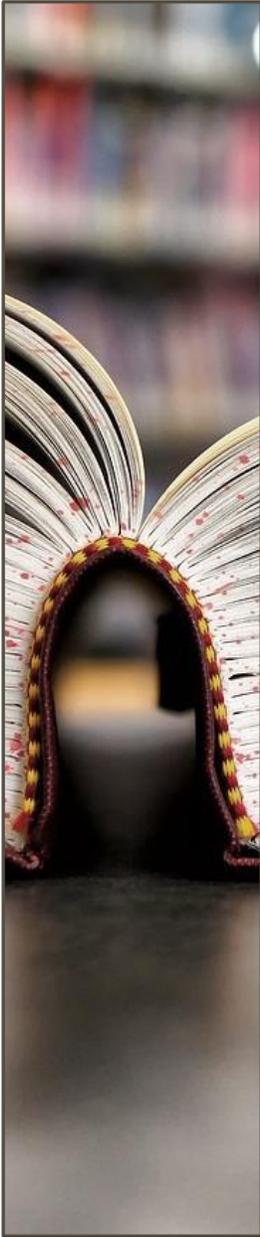


Participants were also asked to identify who should take the lead in their prioritized action. Not surprisingly, all participants noted that the Ministry of Community and Social Services (MCSS) should take the lead in investing in the sector, though some also suggested that this should involve the Ministry of Health and Long-term Care (MOHLTC) (e.g., the Ministry generally, or the long-term care sector specifically). Participants also noted that any current investments in the developmental services sector related to aging were the result of local initiatives, rather than ones that were provincial or system-wide. For example, Elmira District Community Living has developed specialized housing (i.e., Assisted Living Centre) for aging adults in the community with complex or palliative care needs. Most participants were not aware of any related investments.

With respect to designing long-term care to better meet the needs of adults with DD, participants most often indicated that this should be jointly led by the Ministries of Health and Long-term Care and Community and Social Services. Some participants noted instances where local community agencies and long-term care facilities were in the early stages of dialogue to build capacity to support aging individuals. One participant noted that these initiatives have the potential, however, to lead to creation (or re-creation) of institutions for persons with DD.



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## Student Involvement

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Three students at two universities have been involved in our work:

- **Katherine McKenzie** completed a thesis entitled “Aging with intellectual and developmental disabilities: the effect of frailty and health instability on admission to long-term care” towards obtaining her Masters of Science in Epidemiology degree at Queen’s University under the co-supervision of Dr. Ouellette-Kuntz and Dr. Martin (2013-2015).
- **Rachael Shaffer**, a graduate student at Lakehead University, worked as a Research Assistant under the supervision of Dr. Lynn Martin. Rachael contributed to the team’s understanding of the overlap in frailty-related items in the RAI 2.0 (for long-term care) and the RAI-HC (for home care) (2013/2014).
- **Sugeetha Nithiananthan** completed a reading course (LSC1595) on frailty in intellectual disabilities under the supervision of Dr. Ouellette-Kuntz which contributed to her Bachelor of Life Sciences at Queen’s University (2013/2014).

## Scientific Activities

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Since April 2013, we have provided brief and time-sensitive information to the Ministry of Community and Social Services, responded to an applied health research question, presented at eight conferences, and submitted eight articles to peer-reviewed journals.

### **Brief, time-sensitive information to the Ministry of Community and Social Services (MCSS)**

We have provided brief statistical reports to MCSS regarding the number of long-term care residents with developmental disabilities as well as the numbers and proportion of long-term care residents who have dementia.

We relayed that, on census date April 1, 2014, 3.96% of all long-term care residents in Ontario had a DD, and that we also had the capability of providing similar rates going back to 2009, and possibly by age group. We also indicated that according to the RAI 2.0, of the 2897 long-term care residents with DD on April 1, 2014, 224 had a diagnosis of Alzheimer disease (7.7%). On that same day, the proportion without DD affected was 18.5%. Of note is our finding that 3.0% of adults with DD in LTC under the age of 55 had such a diagnosis compared to 1.3% of those without DD of the same age.

## Response to an Applied Health Research Question (AHRQ)

Access the report at:

[https://www.porticowork.ca/documents/38160/99698/Aging\\_AHRQ+report/ac2fb8e7-5a80-457c-913a-7279fd5733b7](https://www.porticowork.ca/documents/38160/99698/Aging_AHRQ+report/ac2fb8e7-5a80-457c-913a-7279fd5733b7)

We presented five main messages in our AHRQ Report:

- Developmental and health services need to plan for an increase in older adults with developmental disabilities in Ontario.
- As early as 50 years of age, adults with developmental disabilities show levels of frailty comparable to older adults without developmental disabilities (80 years and older).
- Frailty and mental health and addiction problems which are more common among adults with developmental disabilities might be contributors to a greater reliance on MOHLTC-funded services including home care and long-term care.
- A considerable number of adults with developmental disabilities living in group homes rely on MOHLTC-funded home care services.
- Many adults with developmental disabilities receiving home care services rely on informal caregivers for everyday supports and emotional supports. This reliance is also seen among individuals who live in group homes. Some informal caregivers report high levels of distress.

Ouellette-Kuntz, H., & Martin, L. (2014, September). Applied Health Research Question Report: Aging profiles of adults with and without developmental disabilities in Ontario. Toronto, ON: Health Care Access Research and Developmental Disabilities Program.

## Submissions to Peer-Reviewed Journals

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

### Published

#### *Health surveillance in older adults with intellectual and developmental disabilities - a review of special considerations*

Increasing life expectancy, shifts to supporting people with intellectual and developmental disabilities in the community, their increased vulnerability to poor health, and the need for greater accountability call for more than occasional studies of aging in this population. Ongoing monitoring of health indicators is feasible in various capacities in different jurisdictions. In this chapter, we first situate the literature about aging with intellectual and developmental disabilities in the context of aging in the general population, and identify key indicators for consideration in health surveillance in older adults with intellectual and developmental disabilities. We then report on a population-based study in Ontario, Canada, which confirms earlier reports of increasing numbers of older adults with intellectual and developmental disabilities, premature aging in this population, and expected trends in use of home care and admission to long-term care. The review concludes with recommendations for future surveillance activities in Ontario and beyond. Concerned researchers should partner with knowledge users/decision makers to maximize the use of electronic administrative and clinical data available to them. In time, the international research community may identify common indicators and methods thereby generating comparators across systems that can further inform policy development.

Ouellette-Kuntz, H., Martin, L., & McKenzie, K. (2015) Health surveillance in older adults with intellectual and developmental disabilities - a review of special considerations. *International Review of Research in Developmental Disabilities*, 48, 151-194. doi:10.1016/bs.irrdd.2015.03.004

***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***

**Background:** The aging population of adults with intellectual and developmental disabilities (IDD) is growing. In the general aging population, frailty is commonly used to predict adverse health outcomes, including hospital use, death, and admission to long-term care. However, existing frailty measures are less appropriate for aging persons with IDD, given their pre-existing conditions and limitations. An accumulation of deficits approach, which is now widely used to describe frailty in the general population, may be more suitable for persons with IDD. Frailty measures specific to persons with IDD have not been widely studied.

**Methods:** Using pre-determined criteria, a frailty index (FI) specific to persons with IDD was developed based on items in the Resident Assessment Instrument – Home Care (RAI-HC), and using the assessments of 7,863 individuals with IDD in Ontario (aged 18-99 years) admitted to home care between April 1st, 2006 and March 31st, 2014. FI scores were derived by dividing deficits present by deficits measured, and categorized into meaningful strata using stratum-specific likelihood ratios. A multinomial logistic regression model identified associations between frailty and individual characteristics.

**Results:** The resulting FI is comprised of 42 deficits across five domains (physiological, psychological, cognitive, social and service use). The mean FI score was 0.22 (SD=0.13), equivalent to 9 deficits. Over half of the cohort was non-frail (FI score < 0.21), while the remaining were either pre-frail (21%, FI score between 0.21 and 0.30) or frail (27%, FI score > 0.30). Controlling for individual characteristics, women were more likely to be frail compared to men (OR=1.39, 95% CI: 1.23-1.56). Individuals who were frail were significantly more likely to have a caregiver who was unable to continue caring (OR=1.86, 95% CI: 1.55-2.22) or feeling distressed (OR=1.54, 95% CI: 1.30-1.83). Living with a family members was significantly protective of frailty (OR=0.35, 95% CI: 0.29-0.41), compared to living alone.

**Conclusions:** Using the FI to identify frailty in adults with IDD is feasible and can be incorporated into existing home care assessments. This could offer case managers assistance in identifying at-risk individuals. Future analyses should evaluate this measure's ability to predict future adverse outcomes.

McKenzie, K., Ouellette-Kuntz, H. & Martin, L. (2015). 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 Geriatrics*, 15(1), 170.  
Read online for free: <http://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-015-0170-5>

### ***Frailty as a predictor of institutionalization among adults with intellectual and developmental disabilities***

*Adults with intellectual and developmental disabilities (IDD) frequently become frail earlier than the general population, resulting in higher care needs. This population is at risk for institutionalization, or re-institutionalization, into long-term care (LTC).*

*Using a retrospective cohort design to follow 3,034 individuals (18-99 years) living in Ontario, Canada and assessed with the Resident Assessment Instrument – Home Care, individuals were characterized with a frailty index (FI) for persons with IDD.*

*Survival analyses determined differences in rates of admission to LTC and survival in the community. Frail individuals had greater rates of admission than non-frail individuals (adjusted HR=2.19, 95% CI: 1.81-2.64). The FI predicts institutionalization.*

McKenzie, K., Ouellette-Kuntz, H. & Martin, L. (2016). Frailty as a predictor of institutionalization among adults with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 54(2), 13-16.

### **Population aging and intellectual and developmental disabilities: Projections for Canada**

*Background:* Population aging is expected to have a dramatic impact on the need for services and supports among adults with intellectual and developmental disabilities. The expected size of the population of older adults affected remains unknown.

*Specific Aims:* The aims of this paper are to present methods to project the age-structure of the adult population with intellectual and developmental disabilities ten years into the future; apply those methods to data from Ontario, Canada; and discuss their relative merit. *Methods:* Two methods were used. The first method relies on knowledge of the prevalence of intellectual and developmental disabilities across age groups in a given population and the corresponding census estimates for future years for the same age groups in that population. The second method requires knowledge of the age-structure of the adult population with intellectual and developmental disabilities as well as age-specific mortality rates for this population. This second method was applied using two sets of available mortality rates.

*Findings:* Projections of the number of adults with intellectual and developmental disabilities 45 to 84 years of age over a 10-year period vary depending on the method used. The first method suggests a moderate increase (20.5%) while the second method suggests a small increase (4.1% to 8.4%) in that age group.

*Discussion:* It is important to be able to critically examine methods and assumptions used when claims are made about population growth and aging in relation to intellectual and developmental disabilities. Accurate age-specific prevalence data and detailed population-level mortality statistics specific to intellectual and developmental disabilities are required to plan for aging-related services.

Ouellette-Kuntz, H., Martin, L., & McKenzie, K. (in press). Population aging and intellectual and developmental disabilities: Projections for Canada. *Journal of Policy and Practice in Intellectual Disabilities*.

***Applying a general measure of frailty to assess the aging-related needs of adults with intellectual and developmental disabilities***

*Background:* Frailty is a concept used to characterize health complexities and identify risk for adverse outcomes among older adults. Adults with intellectual and developmental disabilities often experience premature aging and high levels of frailty.

*Specific aims:* To compare the prevalence of frailty among adults (aged 18-99 years) with and without intellectual and developmental disabilities.

*Methods:* Frailty was measured using the Frailty Marker, based on the Adjusted Clinical Groups-Predicative Model. The occurrence of frailty in a cohort of 51,138 adults with intellectual and developmental disabilities was compared to that in a random sample of 3,272,080 adults without intellectual developmental disabilities.

*Findings:* Approximately 9% of adults with intellectual and developmental disabilities were frail, compared to only 3% in the general population. Women, older adults, and those with mental illness or addiction problems were more likely to be frail.

*Discussion:* Adults with intellectual and developmental disabilities are more often frail, and at earlier ages, compared to the general population. However, this may be attributed to use of a measure of frailty that relies on medical diagnoses; persons with intellectual and developmental disabilities are known to experience higher rates of medical comorbidity. Future research should investigate alternative measures of frailty for persons with intellectual and developmental disabilities, including those that consider changes in health, as well as a broader set of domains (e.g., social characteristics). For a measure of frailty to be more easily and widely used to inform policy and practice, it should ideally be derived from routine standardized assessments.

McKenzie, K., Ouellette-Kuntz, H., & Martin, L. (in press). Applying a general measure of frailty to assess the aging-related needs of adults with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*.

**Care in the community: home care use among adults with intellectual and developmental disabilities over time**

*Background:* Community-based health care services have quickly evolved over the last few decades to respond to the growing population of older adults, and their desire to remain independent in the community. In Ontario, Canada, de-institutionalization has resulted in all persons with intellectual and developmental disabilities living – and aging, in the community.

*Specific aims:* This paper compares use of home care services in Ontario among adults (aged 18-99 years) with and without intellectual and developmental disabilities over time.

*Methods:* Home care use over a 5-year period was compared between a cohort of 46,008 adults with intellectual and developmental disabilities and a random sample of 3,272,080 adults without intellectual and developmental disabilities.

*Findings:* Persons with and without intellectual and developmental disabilities received similar types of home care services. Adults with intellectual and developmental disabilities had much higher rates of admission to home care, and at much earlier ages. While this remained true over time, slight differences by age were noted between groups.

*Discussion:* Higher use at earlier ages suggests that home care services are responding to the needs of adults with intellectual and developmental disabilities. Future research should identify (or develop) best practices for promoting independence in the community for adults with intellectual and developmental disabilities with health care needs.

Martin, L., Ouellette-Kuntz, H., & McKenzie, K. (in press). Care in the community: home care use among adults with intellectual and developmental disabilities over time. *Journal of Policy and Practice in Intellectual Disabilities*.

***The power of population health data in aging and intellectual and developmental disabilities: reactions of knowledge users***

*Background:* Recent work in Ontario (Canada) revealed that adults with intellectual and developmental disabilities 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.

*Specific aims:* This paper describes the reaction of knowledge users to study findings and implications for policy and practice.

*Methods:* A knowledge transfer webinar was held with nearly 200 people; regions of the province, participant types (family members, service providers, decision-makers, researchers), and sectors (health and developmental services) were represented.

*Findings:* Most viewed health and developmental services systems as not ready for the aging population with intellectual and developmental disabilities for two main reasons: insufficient cross-sector expertise and inadequate funding. The need for health care, challenged informal supports, lack of services, and desire for independence were thought to drive higher use of home care among younger adults, while inadequacies within the developmental services sector, challenged informal supports, medical and care needs, lack of community supports, and need for coordinated cross-sector services were noted as contributing to admissions to long-term care.

*Discussion:* There is a lack of evidence-based information on aging and intellectual and developmental disabilities. Ongoing access to quality, population-level data on the number and needs of persons with intellectual disabilities is needed to improve policies and practices to support aging in the community. Persons working in health and developmental services had a shared understanding of the need for system reform, better collaboration, and integration of resources. Both sectors also viewed admission to long-term care as particularly problematic. The province-wide webinar brought together persons with various levels of responsibility from different sectors. Future exchanges should focus on identifying and promoting best practices.

Martin, L., Ouellette-Kuntz, H., & McKenzie, K. (in press). The power of population health data in aging and intellectual and developmental disabilities: reactions of knowledge users. *Journal of Policy and Practice in Intellectual Disabilities*.

***The risk of reinstitutionalization: examining rates of admission to long-term care among adults with intellectual and developmental disabilities over time***

*Background:* Despite efforts towards community living for persons with intellectual and developmental disabilities, there is a risk of re-institutionalization through placement in long-term care facilities.

*Specific Aims:* To examine patterns of admission to long-term care facilities in Ontario, Canada among adults with intellectual and developmental disabilities across key demographic and clinical variables.

*Methods:* A cohort of 50,670 adults with intellectual and developmental disabilities was identified using administrative and clinical health data. Proportions admitted to long-term care between 2009 and 2013 were compared to proportions in a random sample of the general population.

*Findings:* A greater proportion of adults with intellectual and developmental disabilities were admitted to long term care (4.5% vs. 0.9%). Mental health and addiction problems as well as frailty were more strongly associated with admission among adults without intellectual and developmental disabilities. The proportion of adults with intellectual and developmental disabilities admitted annually dropped from 1.6% to 1% while it remained stable among those without disabilities (~0.3%); no change was observed in the proportion of younger adults with intellectual and developmental disabilities.

*Discussion:* A small proportion of younger adults with intellectual and developmental disabilities continue to be admitted to long-term care. Research is needed to understand factors which predict admission in this group as well as age-appropriate alternatives to long-term care.

Ouellette-Kuntz, H., Martin, L., & McKenzie, K. (submitted June 30, 2015). The risk of reinstitutionalization: examining rates of admission to long-term care among adults with intellectual and developmental disabilities over time. *Journal of Policy and Practice in Intellectual Disabilities*.

## Oral & poster presentations at conferences

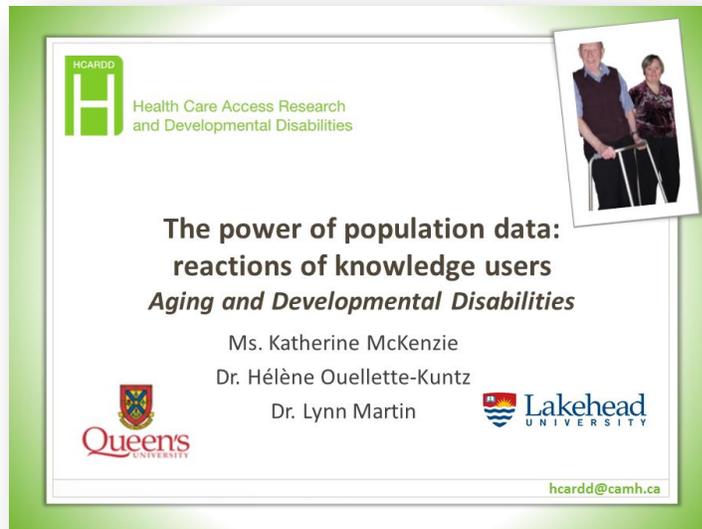
We presented at four conferences.



Balogh, R., Lunsby, Y., Issacs, B., & McKenzie, K. (2015, April). Health Care Access Research and Developmental Disabilities presentation. Presented at the Ontario Association on Developmental Disabilities (OADD) Conference- The Power of the Past Focus on the Future 2015, Thorold, ON, Canada.



Ouellette-Kuntz, H., McKenzie, K. & Martin, L. (2015, July). Development and use of a frailty index for aging adults with intellectual and developmental disabilities. Paper presented at the Global Summit on Innovations in Health and Intellectual and Developmental Disabilities. Los Angeles, California, USA.



Ouellette-Kuntz, H., Martin, L. & McKenzie, K. (2015, October). Adults with intellectual and developmental disabilities in long-term care – the situation in Ontario. Workshop presented at the Health & Wellbeing in Developmental Disabilities Conference, Toronto, Ontario



McKenzie, K., Martin, L. & Ouellette-Kuntz, H. (2016, March). Aging with an intellectual and developmental disability: Home-care, long-term care and frailty. Presented at Aging: Are We Doing It Right? (Centre for Studies in Aging and Health at Providence Care conference), Kingston, Ontario.

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

**Aging and Intellectual and Developmental Disabilities in Home-Care: Frailty & Admission to Long-Term Care**  
 K McKenzie<sup>1</sup>, L Martin<sup>2</sup>, H Ouellette-Kuntz<sup>1</sup>  
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**BACKGROUND**

- The population of persons with intellectual and developmental disabilities (IDD) is aging and has high risk for adverse health outcomes (Dunlop et al., 2013). Compared to the general population, people with IDD have higher rates of frailty (Kuntz et al., 2012).
- The issue of frailty in specialized institutions may have increased the need for home care services. Home care programs with the ability of aging adults to receive at home and receive interventions (Kuntz, Martin, & Ouellette-Kuntz, 2014).
- Long-term care of home care and long-term care use in the Ontario IDD population are not well understood.
- An understanding of frailty and other indicators of IDD population can help identify health needs and inform care practices. Frailty is defined as low energy and physical performance to respond to stressors (Rockwood & Fried, 2008). Frailty is a condition of increasing frailty, which increases over time the probability of adverse health outcomes (Rockwood & Fried, 2008). Frailty is a condition of increasing frailty, which increases over time the probability of adverse health outcomes (Rockwood & Fried, 2008).
- An exploratory measure of frailty could be used to predict potentially avoidable hospitalizations and admissions to long-term care.

**OBJECTIVES**

- Compare frailty in adults with IDD and those without IDD using home care in Ontario.
- Compare frailty and long-term care use in adults with IDD to those without IDD using home care in Ontario.

**KEY REFERENCES**

**METHODS**

Survey of 16,583 adults aged 18-99 years in 2008/09 with IDD eligible for Ontario's Home Care Program and 16,583 adults without IDD eligible for Ontario's Home Care Program in administrative datasets. Data on the Ontario's Home Care Program and Ontario's Home Care Program were used to identify frailty and long-term care use. Data on the Ontario's Home Care Program and Ontario's Home Care Program were used to identify frailty and long-term care use. Data on the Ontario's Home Care Program and Ontario's Home Care Program were used to identify frailty and long-term care use.

**RESULTS**

Figure 1: Proportion of adults with IDD and without IDD using home care in Ontario.

**FOLLOW-UP**

Figure 2: Proportion of adults with IDD and without IDD using home care in Ontario.

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McKenzie, K., Martin, L. & Ouellette Kuntz, H. (2014, October). Aging with Intellectual and Developmental Disabilities: The Effect of Frailty in Home Care Recipients on Time to Admission to Long Term Care. Poster presented at:

- the 2014 Canadian interRAI Conference, Winnipeg, Manitoba.
- Geriatrics 2020 – Bringing Current Issues into Perspective (Centre for Studies in Aging and Health at Providence Care conference), Kingston, Ontario.

**Frailty in Adults with Intellectual & Developmental Disabilities and Admission to Long-Term Care**  
 K McKenzie<sup>1</sup>, H Ouellette-Kuntz<sup>1</sup>, L Martin<sup>2</sup>  
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**Background**

- The population of persons with intellectual and developmental disabilities (IDD) is aging. As their age, adults with IDD face high risk for adverse health outcomes. Compared to the general population, the aging process occurs up to 10 years earlier in adults with IDD.
- An understanding of frailty and other indicators of IDD population can help identify health needs and inform care practices. Frailty is defined as low energy and physical performance to respond to stressors (Rockwood & Fried, 2008). Frailty is a condition of increasing frailty, which increases over time the probability of adverse health outcomes (Rockwood & Fried, 2008).
- An exploratory measure of frailty could be used to predict potentially avoidable hospitalizations and admissions to long-term care.

**Objectives**

- Identify a frailty index (FI) for adults with IDD using Ontario's standardized clinical assessment tool.
- Use frailty to predict the time to admission to long-term care.

**Methods and Materials**

- 1,653 adults aged 18-99 years in 2008/09 with IDD eligible for Ontario's Home Care Program and 16,583 adults without IDD eligible for Ontario's Home Care Program in administrative datasets. Data on the Ontario's Home Care Program and Ontario's Home Care Program were used to identify frailty and long-term care use. Data on the Ontario's Home Care Program and Ontario's Home Care Program were used to identify frailty and long-term care use.
- The frailty index was calculated by summing the frailty index (FI) for each individual. The frailty index (FI) was calculated by summing the frailty index (FI) for each individual. The frailty index (FI) was calculated by summing the frailty index (FI) for each individual.

**Results (Objective 1)**

- The frailty index was calculated by summing the frailty index (FI) for each individual. The frailty index (FI) was calculated by summing the frailty index (FI) for each individual. The frailty index (FI) was calculated by summing the frailty index (FI) for each individual.
- Figure 1 shows the distribution of the frailty index scores. The distribution is right-skewed, with a mean of 0.22 and a median of 0.20. To ease interpretation, scores were categorized into 3 meaningful groups: non-frail (0-0.2), frail (0.21-0.3), and non-frail (0.301-0.5) (Fig. 2).

**Results (Objective 2)**

- Of our sample size of 16,641, 1,653 individuals died between 2008 and 2013, and 1,653 individuals were admitted to long-term care.
- Table 1 shows that the frailty index was significantly associated with the risk of admission to long-term care. The frailty index was significantly associated with the risk of admission to long-term care.

	Non-frail	Frail	Non-frail
Admitted to LTC	813	22,476	586
Dead	883	4,876	278
	813	22,476	586
	883	4,876	278

**Conclusions**

- Frailty increases with age among adults with IDD but they appear to experience frailty earlier than what is typical seen in the general population.
- Further analysis of the time to admission to long-term care is required to better understand the general of the frailty index as a health care indicator. Specifically, a multivariate survival model is necessary to consider covariates such as age, sex, living arrangements, region and caregiver status, while considering the impact of competing risks.
- The frailty index provides a useful measure of vulnerability, and represents the frailty index specifically for the Canadian IDD population. Future research should assess how this frailty index compares to other measures currently used in Ontario.

McKenzie, K., Ouellette-Kuntz, H., & Martin, L. (2015, April). Aging with intellectual and developmental disabilities: The effect of frailty and health instability in home care users on time to admission to long-term care. Poster presented at:

- the OADD Research Special Interest Group 23rd Annual Research Day, St. Catharines, Ontario
- the Queen's University Faculty of Health Sciences Eighteenth Annual Scientific Meeting for Health Science Research Trainees, Kingston, Ontario
- the 2015 Canadian Society for Epidemiology and Biostatistics (CSEB) Conference, Toronto, Ontario

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