



Health Care Access Research
and Developmental Disabilities

HEALTH CARE ACCESS RESEARCH AND
DEVELOPMENTAL DISABILITIES (H-CARDD)

September 2014



Applied Health Research Question Report: Aging profiles of adults with and without developmental disabilities in Ontario

Prepared for Reena and the Seniors' Health Knowledge Exchange Network
Authors

Dr. Hélène Ouellette-Kuntz, Queen's University, Kingston, Ontario [helene.kuntz@queensu.ca]

Dr. Lynn Martin, Lakehead University, Thunder Bay, Ontario [lynn.martin@lakeheadu.ca]



Lakehead
UNIVERSITY



Queen's
UNIVERSITY

Contents

List of Figures	ii
List of Tables.....	iii
About H-CARDD.....	iv
Main Messages	v
Executive Summary	vi
Context	1
Methods	3
Results	5
AREA 1: Population profiles and projections based on age.....	5
AREA 2: Frailty	9
AREA 3: Group homes	13
Characteristics of adults with developmental disabilities in group home settings.....	13
Adults with developmental disabilities living in group homes receiving home care services.....	15
Personal characteristics	15
Formal services	16
Informal support	18
Discussion and Further Research	21
Conclusions	23
References	24
Appendix 1: Technical Definitions	26

List of Figures

Figure 1: Age Distribution of Two Cohorts.....5

Figure 2: Number of Adults with Developmental Disabilities by Age Category (2009/2010).....6

Figure 3: Breakdown of the Number of Adults with Developmental Disabilities 18 to 84 years of age in 2009/10 and Projected Numbers by Age Group in 2015 and 2021 based on Census and Prevalence Information.....7

Figure 4: Number of Adults with Developmental Disabilities 35 years and older in 2009/10 Projected in 2015 and 2021 based on Age-Specific Mortality Rates.....7

Figure 5: Proportion of Adults with Developmental Disabilities by Neighbourhood Income Level.....8

Figure 6: Proportion of Adults with and without Developmental Disabilities who are Frail as per the Frailty Marker.....9

Figure 7a: Proportion of Adults with and without Developmental Disabilities receiving Home Care who are Frail as per the CHES.....11

Figure 7b: Proportion of Adults with and without Developmental Disabilities receiving Home Care who are Frail as per the Frailty Marker.....11

Figure 8a: Proportion of Adults with and without Developmental Disabilities in Long-Term Care who are Frail as per the CHES.....12

Figure 8b: Proportion of Adults with and without Developmental Disabilities in Long-Term Care who are Frail as per the Frailty Marker.....12

Figure 9: Age Distribution in Group Home Subset and Overall Aging Cohort.....13

Figure 10: Distribution Across Neighbourhood Income Level for Group Home Subset and Overall Aging Cohort.....14

Figure 11: Distribution of Group Home Subset and Overall Aging Cohort by LHIN.....14

Figure 12: Proportion of Group Home Residents receiving Home Care by LHIN.....16

Figure 13: Proportion of Group Home Subset and Overall Aging Sample Receiving Home Care by Specific Service.....17

Figure 14: Informal Supports’ Relationship to Adults with Developmental Disabilities among those with Informal Supports.....19

Figure 15: Type of Support Provided by Informal Supports.....19

Figure 16: Status of Informal Support.....20

List of Tables

Table 1: Prevalence of Developmental Disabilities in Ontario by Age Group (2009/2010).....	6
Table 2: Demographic Characteristics of Group Home Residents receiving Home Care.....	15
Table 3: Medication Use and Oversight among Group Home Subset and Overall Aging Sample Receiving Home Care Services.....	17
Table 4: Hospital use in the last 90 days among Group Home Subset and Overall Aging Sample Receiving Home Care Services.....	18
<u>Table 5: Hours of Informal Support Provided to those who had Informal Supports.....</u>	<u>20</u>

About H-CARDD

Health Care Access Research and Developmental Disabilities (H-CARDD) is a research program that aims to enhance the overall health and wellbeing of individuals with developmental disabilities through improved health care policy and improved services. H-CARDD research is conducted by dedicated teams of scientists, policymakers, and health care providers, working collaboratively.

H-CARDD's partners include the Ontario Ministry of Community and Social Services, the Ontario Ministry of Health and Long-Term Care, the Centre for Addiction and Mental Health, the Institute for Clinical Evaluative Sciences, Surrey Place Centre, the University of Toronto, the University of Ottawa, Queen's University, York University, Lakehead University, Sunnybrook Hospital, the University of Ontario Institute of Technology, and Women's College Hospital.

H-CARDD is currently funded by the Canadian Institutes of Health Research Partnerships for Health System Improvement program (PHE # 103973) and the Ontario Ministry of Health and Long-Term Care Health Systems Research Fund (Ministry Grant #06671).

This report is in response to an Applied Health Research Question posed to the H-CARDD Program by Reena and the Seniors' Health Knowledge Exchange Network. The opinions, results and conclusions in this report are those of the authors and are not necessarily those of the funding sources or H-CARDD's partners. No endorsement by the Ontario Ministry of Health and Long Term Care, the Ministry of Community and Social Services or the Institute for Clinical Evaluative Sciences is intended or should be inferred.

How to cite this report

Ouellette-Kuntz, H., & Martin, L. (2014). 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.

Main Messages

- 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.

Executive Summary

Discussions with stakeholders revealed a need for greater understanding of how aging among adults with developmental disabilities is likely to affect service needs in the future. Particular information needs identified related to projections of the population's age distribution, the occurrence of frailty, use of long-term care and home care, and supports provided to those living in group homes.

A cohort of adults with developmental disabilities 18 to 99 years of age was created using ICES-held databases. Samples receiving home care services and subsets living in group homes were also identified. Census data and age-specific mortality rates were used to develop population projections to 2015 and 2021. Two measures of frailty were examined in relevant samples.

Age-related frailty is known to be associated with negative outcomes including increased use of services. By 2021, it is projected that the number of adults with developmental disabilities over the age of 64 will be almost double what it was in 2009/2010. The occurrence of frailty among adults with developmental disabilities is higher than among those without developmental disabilities. Early work has shown that as early as 40 years of age frailty appears in approximately 8% of adults with developmental disabilities. This proportion is not reached until after 75 years of age among adults without developmental disabilities.

- Ongoing monitoring of the population (demographics) and its health care needs should be undertaken. More research is needed regarding the feasibility and utility of adapting frailty measures specific to developmental disabilities in clinical settings and for use when analyzing administrative data.

Despite being younger, adults with developmental disabilities are more likely to have used home care (13% versus 4%) and long-term care (12% versus 1%) in the four year period after April 1, 2009. A high proportion of home care recipients with developmental disabilities had recently visited the hospital emergency department or been hospitalized. Regional variations in use of home care services by adults with developmental disabilities are evident. Among those living in group homes, a variety of home care services are provided including homemaking and procedures.

- Further investigation into regional policies related to use of home care services by persons living in group homes and the roles of health and developmental services providers may be warranted.

Many adults with developmental disabilities receiving home care services rely on informal caregivers; this is also true for those who live in group homes. Some informal caregivers report high levels of distress.

- There is value in further work exploring the prevalence of distress among caregivers of persons not living in group home settings as this inform policies and strategies aimed at preventing crisis.

Context

In 2013, the H-CARDD research team received a grant from the Ontario Ministry of Health and Long-Term Care Health System Research Fund to address health disparities experienced by adults with developmental disabilities in Ontario. Among the foci of the work to be undertaken in the 3-year funding period is one concerning aging. The Aging Study is informed by the province's *Aging at Home Strategy* which seeks to build community capacity to help older adults live independently, and in good health, in their home. The project aims to examine the extent to which health care services coordinated through Community Care Access Centres (CCACs) developed for the "average consumer" are meeting the needs of adults with developmental disabilities as they age. The Aging Study will answer three related research questions:

- 1) Are there differences in the profile of adults 40 years and older with and without developmental disabilities?
- 2) What are the rates of admission to long-term care (LTC) and home care for adults with developmental disabilities?
- 3) What factors predict admission to LTC among home care recipients with developmental disabilities?

The study is co-lead by Lynn Martin of Lakehead University and H el ene Ouellette-Kuntz of Queen's University who work closely with key knowledge users: Sandy Stemp of the Ontario Partnership on Aging and Developmental Disabilities (who also represents Reena and the Seniors' Health Knowledge Exchange Network), Rosa Carlucci and Rachel Ortiz from the Ontario Ministry of Community and Social Services' Community Supports Policy Branch, and Robert Francis from the Ontario Ministry of Health and Long-term Care.

This report is in response to an Applied Health Research Question (AHRQ) regarding the need for enhanced information on the population profile and how individuals living in group homes are supported through home care. The AHRQ relates to three particular issues identified when preliminary results were shared with knowledge users:

- 1) Preliminary analyses from the Aging Study revealed a dip in the numbers of adults with developmental disabilities aged 40-44 years.

- Area 1: There is a need to better understand the age breakdown of the adult population with developmental disabilities and to develop projections of the population's age distribution.

- 2) Early work in the Aging Study also showed that signs of frailty (as measured by the Johns Hopkins Frailty Marker) appeared as early as 40 years of age among adults with developmental disabilities; a similar prevalence of frailty was not observed until 75 years of age or more among a comparison sample of adults without developmental disabilities. There was concern that the Frailty Marker may overestimate frailty in populations with disabilities.

- Area 2: There is a need to better understand at what age differences in frailty first appear among adults with and without developmental disabilities, as well as whether other available measures might be more useful in understanding frailty among adults with developmental disabilities.

3) Ontario has significantly invested in community-based living for adults with developmental disabilities, having closed all specialized institutions in March 2009. The province is also committed to community-based living for older adults, having announced a 1.1 billion *Aging at Home Strategy* in 2010. There is concern that persons with developmental disabilities may have distinct home care needs and that those in Developmental Services residential settings may not access home care services in the same way as others.

- Area 3: There is a need to understand how adults with developmental disabilities living in Developmental Services residential settings (e.g., group homes) are supported through home care, as well as the informal care these home care clients receive.

Methods

AREA 1: Population profiles and projections based on age

A new cohort (18 to 99 years of age) was created based on the H-CARDD cohort (18 to 64 years of age; see Lin *et al.*, 2013) in order to study aging. The Aging cohort excludes individuals only identified as having a developmental disability through the disability income support program (MCSS dataset) which is restricted to individuals 18 to 64 years of age¹ but it extends identification in health administrative datasets from 65 to 99 years in the original five datasets (Discharge Abstract Database, Same Day Surgery Database, Ontario Mental Health Reporting System, National Ambulatory Care Reporting System, and Ontario Health Insurance Plan) and searches for developmental disability codes in two additional health datasets: the Chronic Care Reporting System for Long-Term Care and the Home Care Database. These datasets were linked using unique, encoded identifiers and analyzed at the Institute for Clinical Evaluative Sciences (ICES). The resulting Aging cohort includes over 50,000 adults who were 18 to 99 years of age in 2009/10. Unless otherwise specified, the analyses in this report use this Aging cohort and reflect data for the 2009/2010 fiscal year.

The Aging cohort was compared to a random sample of 20% of the population without developmental disabilities (18 to 99 years of age) eligible for MOHLTC-funded health services. The two cohorts are described across key demographic (age, sex, urban/rural living, neighbourhood income, region of residence), clinical (presence of mental illness or addiction, frailty) and service use (home care, long-term care) variables.

Age-specific prevalence proportions for developmental disabilities were calculated using inter-censal population estimates for 2009 from Statistics Canada.

Two approaches were used to project the number of adults with developmental disabilities expected in 2015 and 2021 by age group. In the first instance, we applied the 2009/10 age-specific prevalence figures to projected population sizes for Ontario (Method 1). The second approach consisted of applying age-specific mortality rates derived from a community-based sample of adults with developmental disabilities over a seven year period (2004-2011) (Ouellette-Kuntz & Wilkinson, 2013) to 5-year birth cohorts of the Aging cohort (Method 2).

AREA 2: Frailty

To better understand frailty in relation to aging in persons with developmental disabilities, a literature review was conducted and two measures were compared: the Johns Hopkins Frailty Marker and the CHES. The comparison of measures was restricted to persons in the Aging cohort who had received either home care or long-term care services. This was necessary since one of the measures considered (i.e., the CHES) is embedded in instruments from the interRAI suite (see www.interrai.org) which are used in those settings. The RAI-Home Care (RAI-HC)

¹ This exclusion was deemed necessary so as not to unduly bias the probability of identification.

assessment is completed as part of regular clinical practice in all of Ontario's Community Care Access Centres (CCACs), while the RAI 2.0 assessment has been mandated for use in long-term care homes across the province.

Since the Johns Hopkins Frailty Marker uses a 2-year look-back window (fiscal years 2007/2008 and 2008/2009) whereas the CHES measures functioning at the time of assessment; we restricted our comparative analyses to those among the Aging cohort who had one or more home care assessment (n=4,510) and a long-term care assessment (n=1,564) between April 1, 2007 and March 31, 2009.

AREA 3: Group Home Residents

Overall, a total of 6,522 individuals in the Aging cohort were identified as living in group homes (see Technical Definitions section). Select comparisons were made (i.e., age, sex, income quintile, and area of residence) between persons with developmental disabilities (18 to 99 years of age) identified as living in group homes to the overall Aging cohort (n=51,138, which includes the 6,522 persons living in group homes).

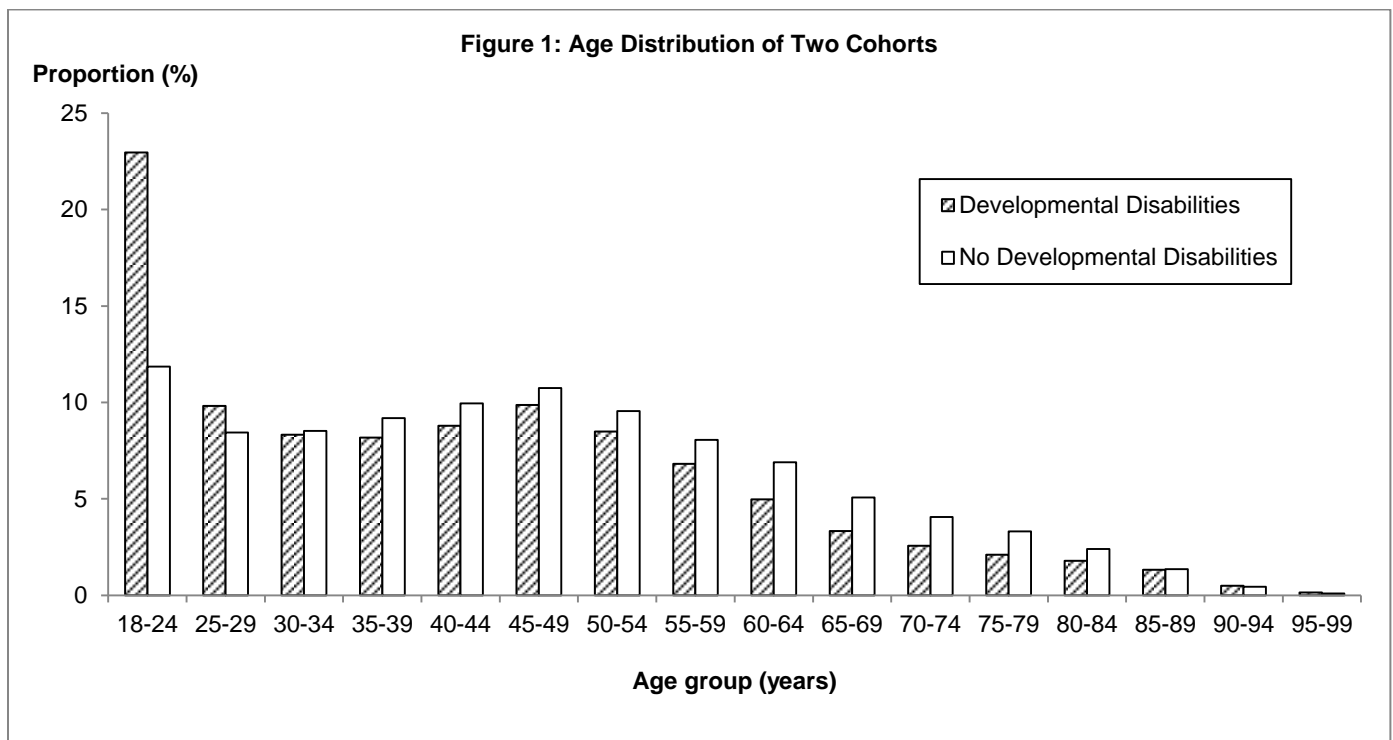
Information on the needs of adults with developmental disabilities living in group homes and receiving informal care were restricted to persons in the Aging cohort who had received home care services in 2009/10. Restricting to home care recipients was necessary as this type of information is only available through the RAI-HC assessment. Restricting the time frame to 2009/10 was necessary since confirmation of living arrangement for those identified only in ODSP as living in a group home could not be confirmed beyond that year. A total of 1,470 of individuals in the Aging cohort had a RAI-HC assessment available for 2009/10, 292 of which lived in a group home (approximately 20%). Select comparisons were made with respect to personal characteristics (i.e., age, sex, income quintile, and area of residence) between adults with developmental disabilities living in group homes and the full sample of adults with developmental disabilities receiving home care services. The use of formal services and informal support was also compared.

Note that examination of informal support (i.e., relationship, types of support provided, and status of informal support) is restricted to the subset of individuals who had a RAI-HC assessment which indicated they had informal support present. This represents 231 of 292 adults in group homes (79.1%), and 1,326 of 1,470 adults in the overall sample (90.2%).

Results

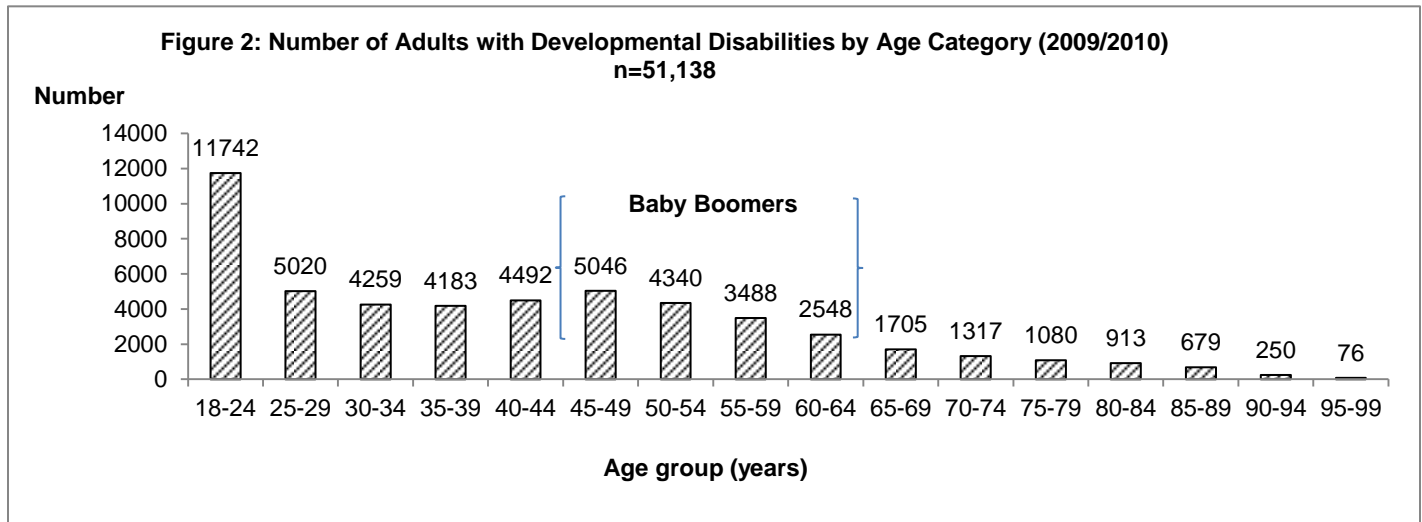
AREA 1: Population profiles and projections based on age

The Aging cohort is comprised of 51,138 adults 18 to 99 years of age with developmental disabilities living in Ontario in 2009/10. The comparison cohort includes 3,323,408 adults without developmental disabilities aged 18-99 years living in Ontario in the same year. As shown in Figure 1, the cohort of adults with developmental disabilities is younger than the comparison cohort with a significantly greater proportion of individuals in the youngest age group (18 to 24 years).



The drop in proportion of adults with developmental disabilities 40-44 years of age seen in our preliminary analysis persists through to those aged 30 to 34. The proportions increase again in the two youngest age groups.

A closer look at the numbers by age category (Figure 2) reveals that the first anomaly is in the high numbers of individuals 45 to 64 years of age which can be accounted for by the baby boom following the Second World War - those born 1946 to 1965 who would be 45 to 64 in 2009/10 (Statistics Canada, 2011).



The second anomaly - the very high number of adults in the youngest age group – though it includes the baby boom echo generation (born 1982 to 1996; 13 to 27 years of age in 2009), is not due to a population increase. The prevalence of developmental disabilities among those 18 to 24 years of age is 0.94% compared to 0.50% among those 25 to 44 years olds (see Table 1). The dramatic change in prevalence is most likely due to the increase in the prevalence of autism spectrum disorder in Ontario and elsewhere since the 1980s (Ouellette-Kuntz *et al.*, 2013).

Table 1: Prevalence of Developmental Disabilities in Ontario by Age Group (2009/2010)

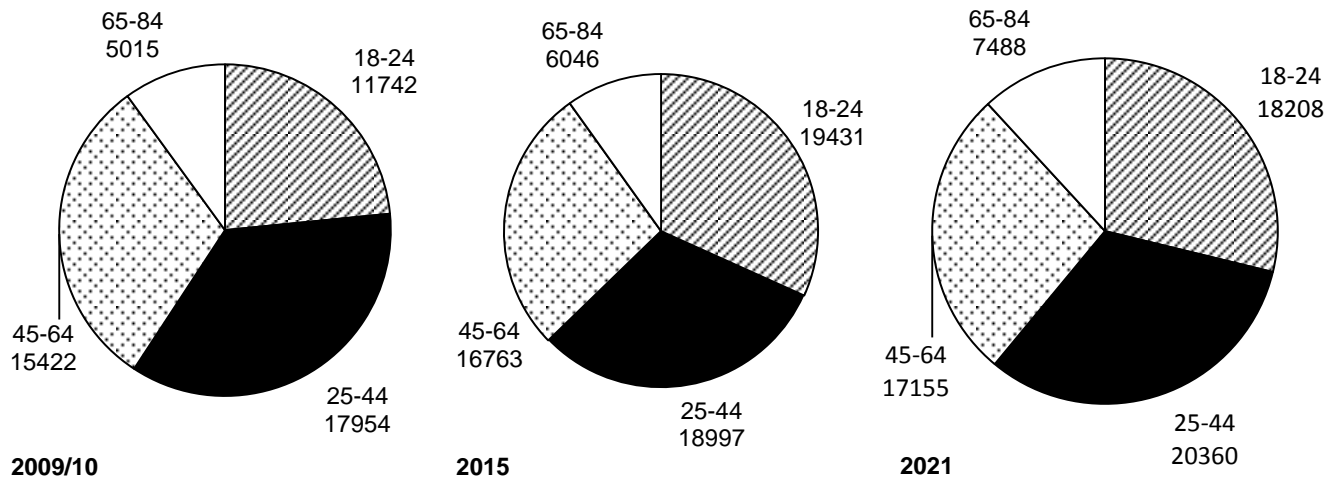
Age Group ²	Number of Adults with Developmental Disabilities in Ontario (2009/2010)	Population of Ontario (2009)*	Prevalence
18-24 years	11,742	1,254,302	0.94%
25-44 years	17,954	3,615,705	0.50%
45-64 years	15,422	3,600,209	0.43%
65-84 years	5,015	1,556,456	0.32%

*<http://www5.statcan.gc.ca/cansim/a26>

² Due to small numbers, prevalence for the group 85 years and older is not reported.

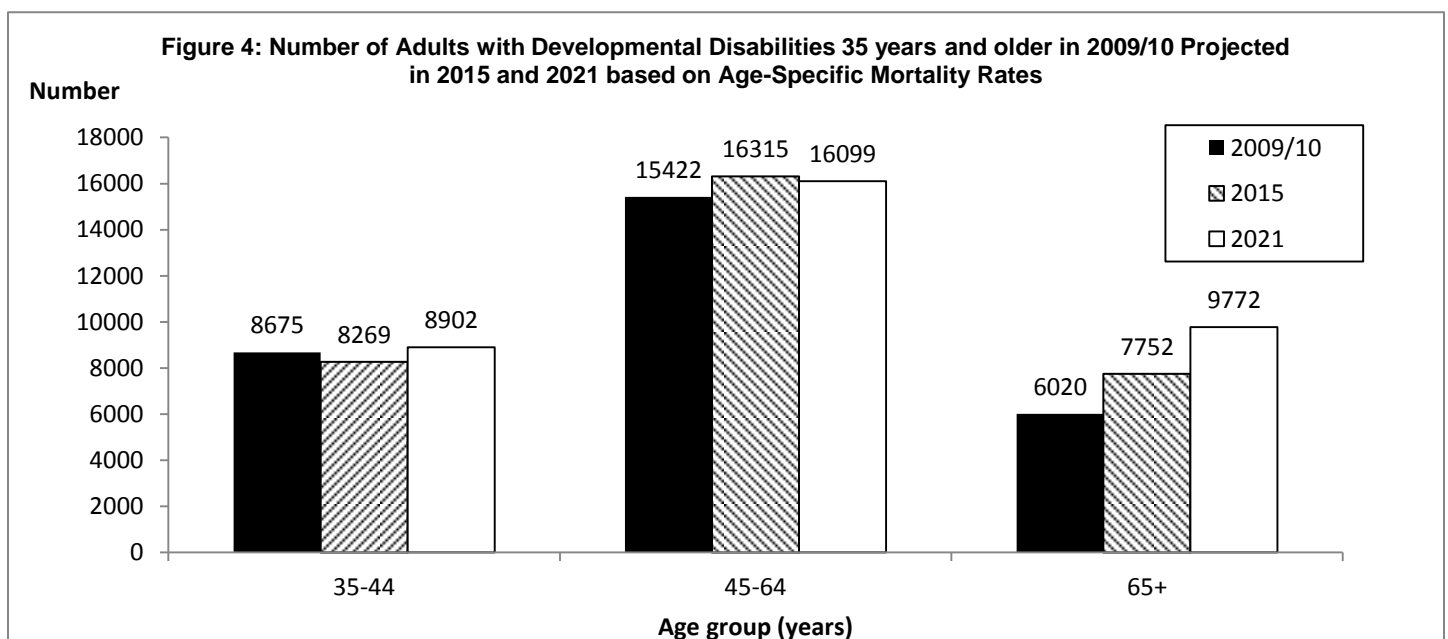
With respect to population projections, Method 1 shows large increases in the numbers of individuals in the youngest and oldest age groups projected by 2015 (Figure 3). Of note is the high relative increase among those 65 to 84 years of age (5,015 in 2009/10 to 7,488 in 2021 represents a 1.5 time increase in numbers).

Figure 3: Breakdown of the Number of Adults with Developmental Disabilities 18 to 84 years of age in 2009/10 and Projected Numbers by Age Group in 2015 and 2021 based on Census and Prevalence Information

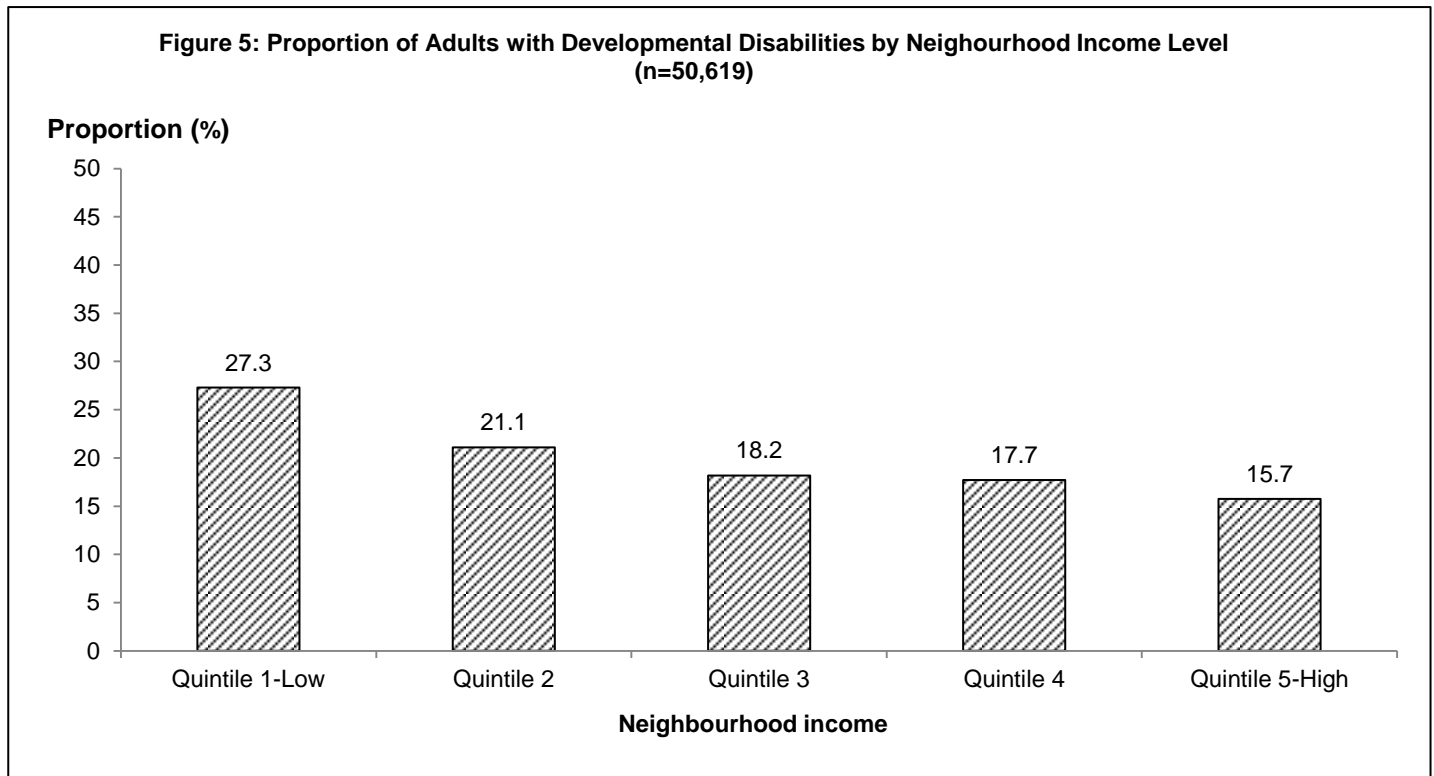


Using Method 2, age groups were further collapsed and the youngest age groups were excluded. Figure 4 depicts the projected number of adults with developmental disabilities in 2015 and 2021 relative to the numbers in 2009/10 for three age groups. As shown, the age group seeing the greatest change is the oldest. By 2021, it is projected that the number of adults with developmental disabilities over the age of 64 will be over 1.6 times what it was in 2009/10.

Figure 4: Number of Adults with Developmental Disabilities 35 years and older in 2009/10 Projected in 2015 and 2021 based on Age-Specific Mortality Rates



Besides the age distribution, the two cohorts differ significantly across several key variables. There are proportionally more men in the developmental disabilities cohort (55.8% versus 48.2%). Those with developmental disabilities are more likely to live in rural areas of the province (15.3% versus 11.5% with a slight over representation in the South East and North East LHIN areas) and in the poorest neighbourhoods (see Figure 5).



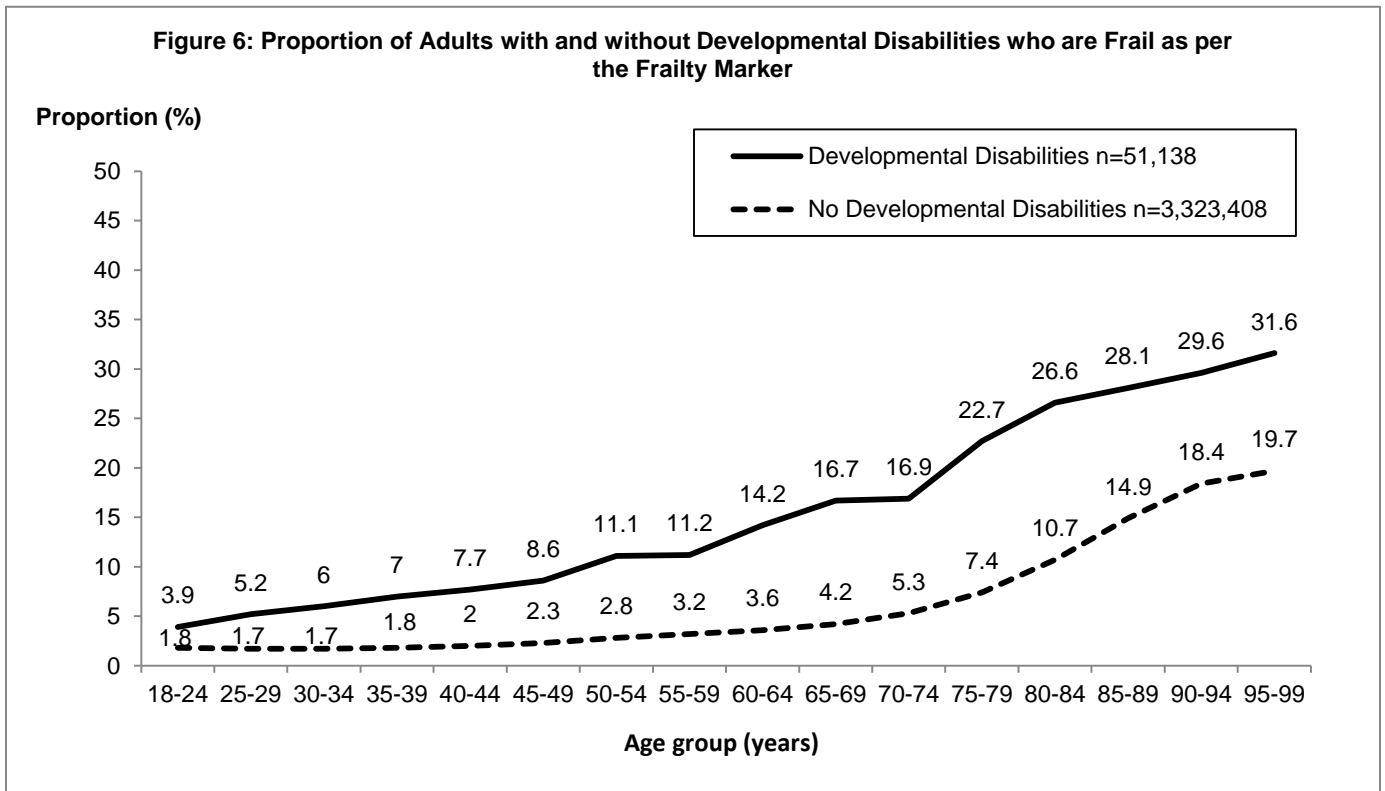
Adults with developmental disabilities are more likely to have a diagnosed mental health or addiction problem (50.6% versus 27.1%) and to be frail (8.9% versus 3.1%; as per the Frailty Marker). They are more likely to have had a home care assessment (12.5% versus 3.6%) and a long-term care assessment (11.6% versus 1.4%) in the four year period after April 1, 2009.

AREA 2: Frailty

As part of the H-CARDD Aging study, we set out to compare frailty among adults with and without developmental disabilities using a measure commonly used in Ontario: the **Frailty Marker** (see insert). Our intent was to use this measure to understand when ‘aging’ begins for persons with developmental disabilities. Since, our preliminary analyses identified that the proportion who were frail in our youngest age group (adults with developmental disabilities aged 40-44 years) was comparable to that among 75-79 year olds in the comparison cohort (i.e., 7.7% and 7.4%, respectively), we extended the cohorts to include adults from ages 18 to 99 years, rather than limit to those aged 40 to 99 years.

Overall, the occurrence of frailty was much higher among adults (18 to 99 years) with developmental disabilities (8.9%) than among those without (3.1%). Examination of frailty across age groups (see Figure 6) showed that the proportion of adults 18 to 24 years of age with developmental disabilities who were frail was comparable to that among 60-64 year olds without developmental disabilities (3.9% and 3.6%, respectively).

The **Frailty Marker** was developed at Johns Hopkins. It is based on the Adjusted Clinical Groups-Predicative Model (ACG-PM) which was designed to determine the impact frail or disabled individuals have on future resources. The ACG-PM considers 81 diagnostic codes that clinically describe frailty, and groups them into 11 clusters, each representing a distinct condition associated with frailty. Individuals who have a diagnosis within one of the 11 clusters are deemed frail.



Given the high overall proportion of adults with developmental disabilities coded as frail using the Frailty Marker, the inability to clearly relate the measure to aging due to its high prevalence in younger adults, and the knowledge that the Frailty Marker was designed to identify needs based on either age or disability, we queried whether this measure was appropriate for use as an indicator of age-related decline in adults with developmental disabilities. A literature review on frailty and developmental disabilities (Nithiananthan, 2014) revealed a recent interest in measures of frailty adapted to the unique health and developmental needs of individuals with developmental disabilities. These recognize that individuals with developmental disabilities have pre-existing deficits that need to be taken into consideration when characterizing frailty (Brehmer-Rinderer, Zeilinger, Radaljelvic, & Weber, 2013). The Frailty Index developed in the Netherlands (Schoufour *et al.*, 2013) considers 51 deficits related to the social, physical, and psychological components of health. The Vienna Frailty Questionnaire similarly measures frailty based on 4 domains of functioning: social, cognitive, physiological, and physical (Brehmer-Rinderer *et al.*, 2013). These measures however rely on detailed clinical information much of which is not available in health administrative data.

The Changes in Health, End Stage disease, Signs, and Symptoms (CHESS) scale

uses an algorithm based on the presence or absence of nine issues related to frailty in older populations, including: cognitive decline; decline in performance of activities of daily living; shortness of breath; dehydration or insufficient fluid intake; edema; vomiting; weight loss; decrease in amount of fluid or food consumed; and instability of conditions.

An alternative measure available through RAI-HC and RAI 2.0 is the **CHESS scale** (see insert). We therefore investigated whether the diagnosis-based ACG System (Frailty Marker) and the CHESS provide comparable estimates of 'frailty'. As noted earlier, the CHESS scale is available in the Ministry of Health and Long-Term Care administrative datasets for those who have been assessed for home care or long-term care. As such, comparisons are restricted to the subset of adults with and without developmental disabilities who have received either home care or long-term care services.

As expected, the subsets of individuals who receive home care services are more likely to be frail at younger ages than the overall cohorts (with or without developmental disabilities) whether measured by the CHESS or the Frailty Marker. See figures 7a and 7b. This pattern was more pronounced among those without developmental disabilities. Interestingly, among Home Care recipients, adults with developmental disabilities are less likely than those without developmental disabilities to be frail as per the CHESS until the age of 70 whereas proportionately more of them are frail as early as 40 years of age when using the Frailty Marker.

Figure 7a: Proportion of Adults with and without Developmental Disabilities receiving Home Care who are Frail as per the CHES

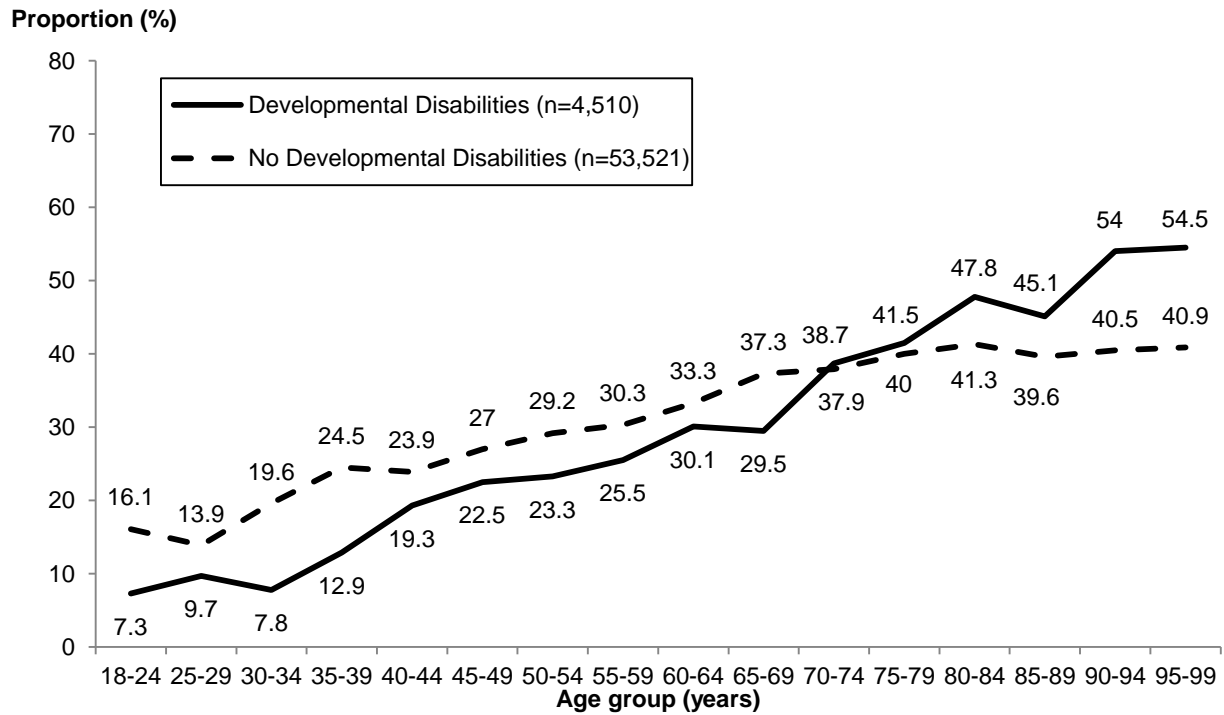
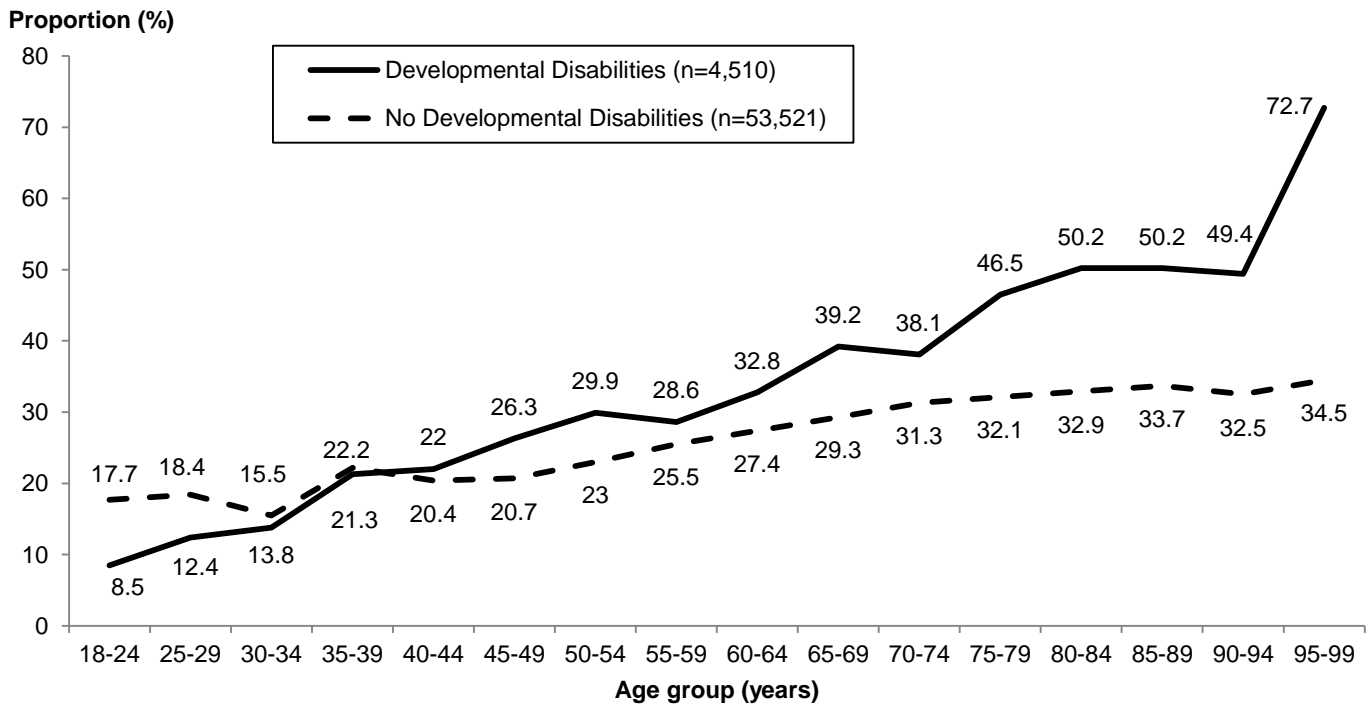
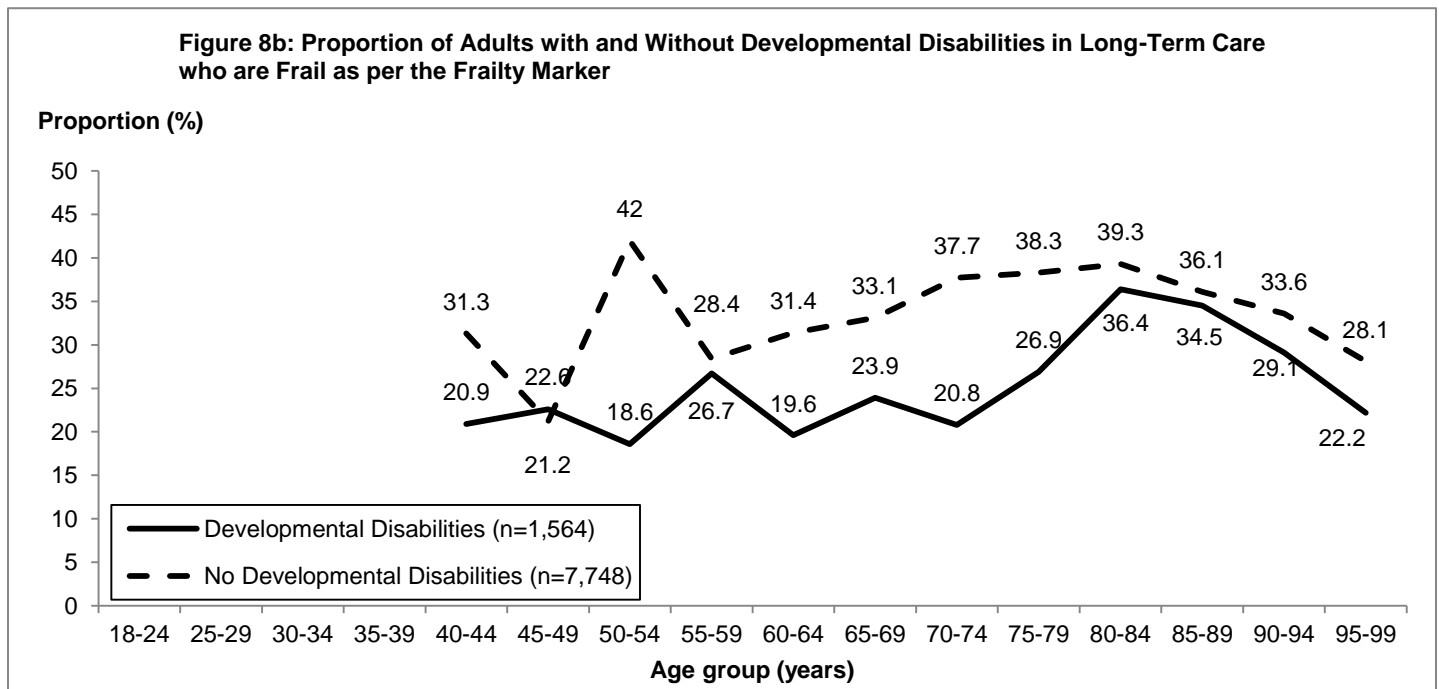
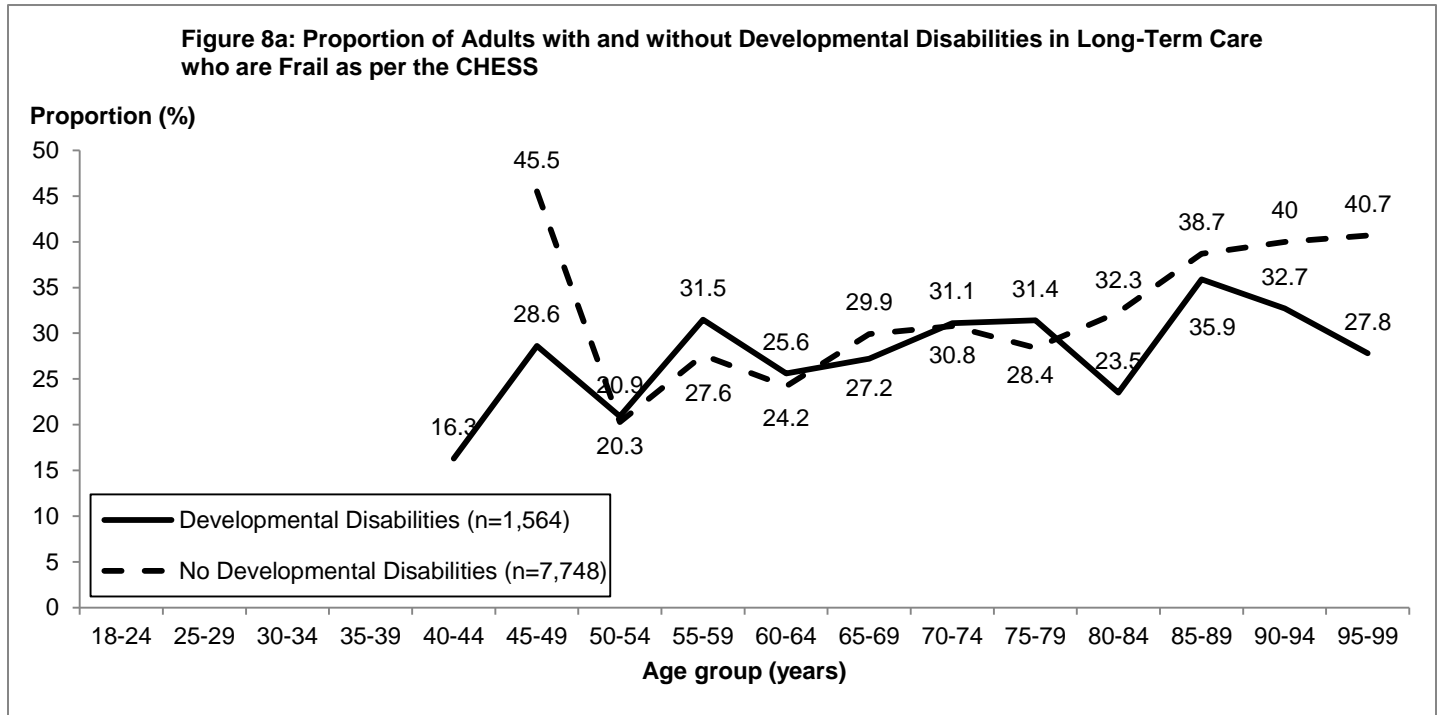


Figure 7b: Proportion of Adults with and without Developmental Disabilities receiving Home Care who are Frail as per the Frailty Marker



Similarly, frailty is more common among residents of long-term care. In these subsets there is less of a relationship between frailty and age as they may be independent factors leading to an admission to long-term care. Adults with developmental disabilities assessed for long-term care appear to be less frail at younger ages than their counterparts without developmental disabilities when the Frailty Marker is used.



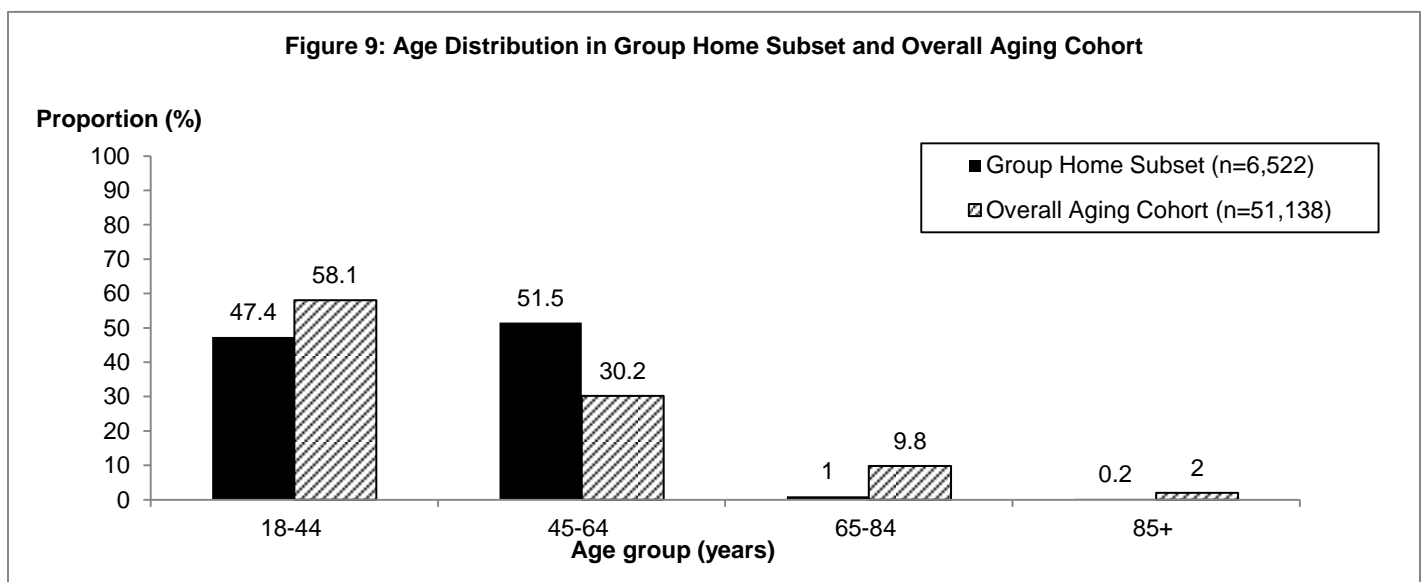
NOTE: values are suppressed for younger age groups due to small cells.

AREA 3: Group homes

Characteristics of adults with developmental disabilities in group home settings

Overall, a total of 6,522 individuals in the Aging cohort were identified as living in group homes. In this section, information is provided on the personal characteristics of adults with developmental disabilities living in group homes and on the overall Aging cohort (n=51,138, which includes the 6,522 persons living in group homes³).

As shown in Figure 9, the vast majority of adults with developmental disabilities were under 65 years of age: 58.1% were 18-44 years, 30.2% were 45-64 years, and 11.8% were 65 years of age or more. Among the subset living in group homes, just over half (51.5%) were aged 45-64 years and just under half (47.4%) were in the 18-44 year age group; a very small proportion of adults with developmental disabilities 65 years or more lived in group homes (1.2%). This reflects the way in which those living in group homes were identified (see Technical Definitions Appendix) and should not be interpreted as indicative of actual population age distribution among those living in group homes.

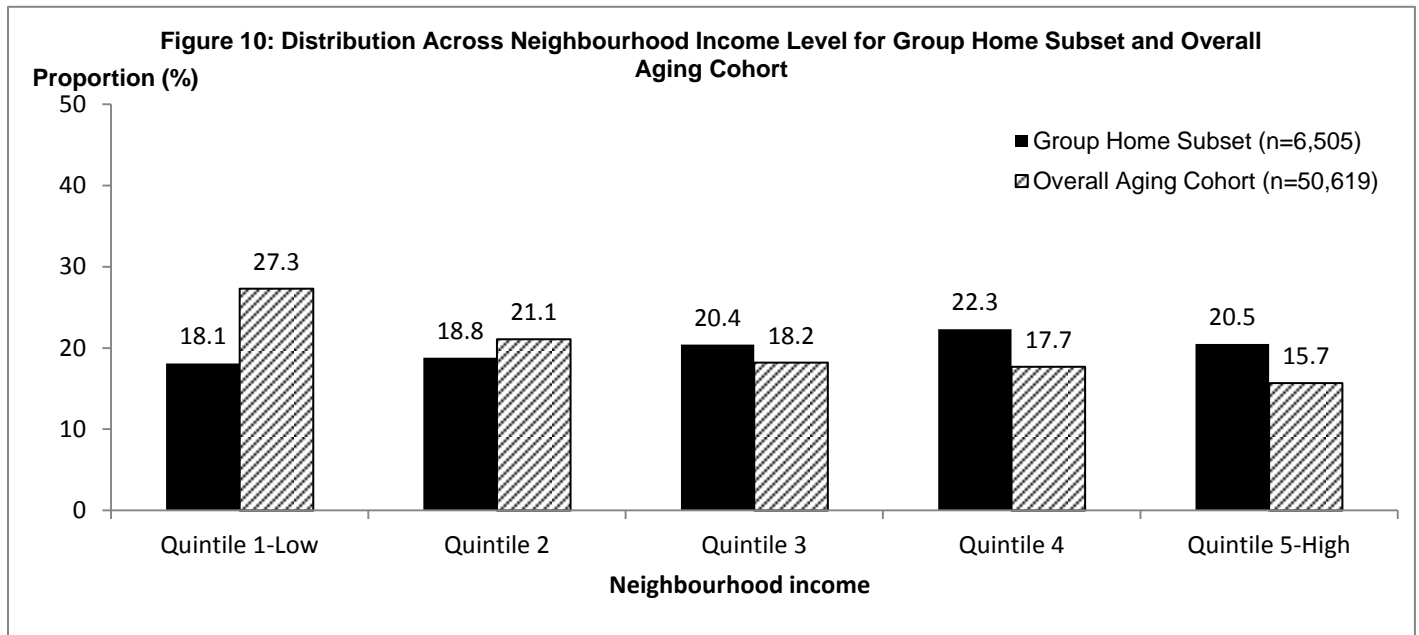


Overall, there were more males (55.8%) than females, and this was true among the subset living in group homes (59.4%). It should be noted that no age-related differences among men and women in terms of group home status were identified (i.e., the same age distribution patterns were present among both women and men).

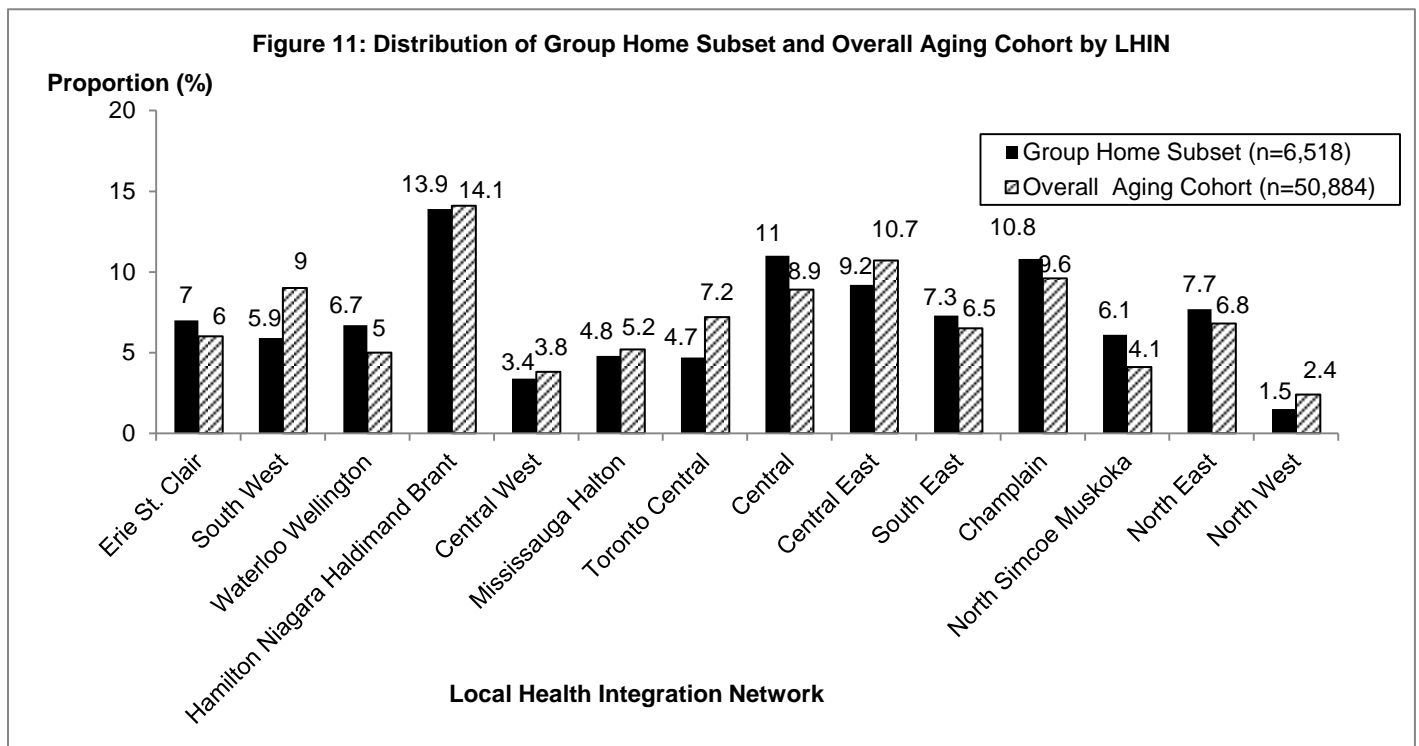
As shown in Figure 10, overall, a large proportion of adults with developmental disabilities lived in poorer neighbourhoods. More specifically, almost half (47.9%) were in the bottom two quintiles, 18.0% were in the

³ We chose to compare the group home residents to the entire Aging cohort due to the uncertainty in the ability to identify all individuals residing in group homes. As such, the group home and overall results should be interpreted as distinct findings with group home being a subset of overall.

middle category, and about one third (33.1%) were in the two highest income quintiles. A different pattern emerged among the subset living in group homes. Here, there were more people living in higher income neighbourhoods (42.8%) and fewer in lower income neighbourhoods (36.9%).



In both the overall Aging cohort and the subset of adults living in group homes, over 80% resided in urban areas. Further, in both cases, the highest proportion of individuals lived in the Hamilton Niagara Haldimand Brant region, and the fewest in the North West region. See Figure 11.



Adults with developmental disabilities living in group homes and receiving home care services

As stated previously (see Methods section), information on the support needs and informal care of adults with developmental disabilities living in group homes was restricted to persons in the Aging cohort who had received home care services, as this type of information is only available through the RAI-HC assessment. A total of 1,470 of individuals in the Aging cohort had a RAI-HC assessment available, 292 of which lived in a group home (approximately 20%).

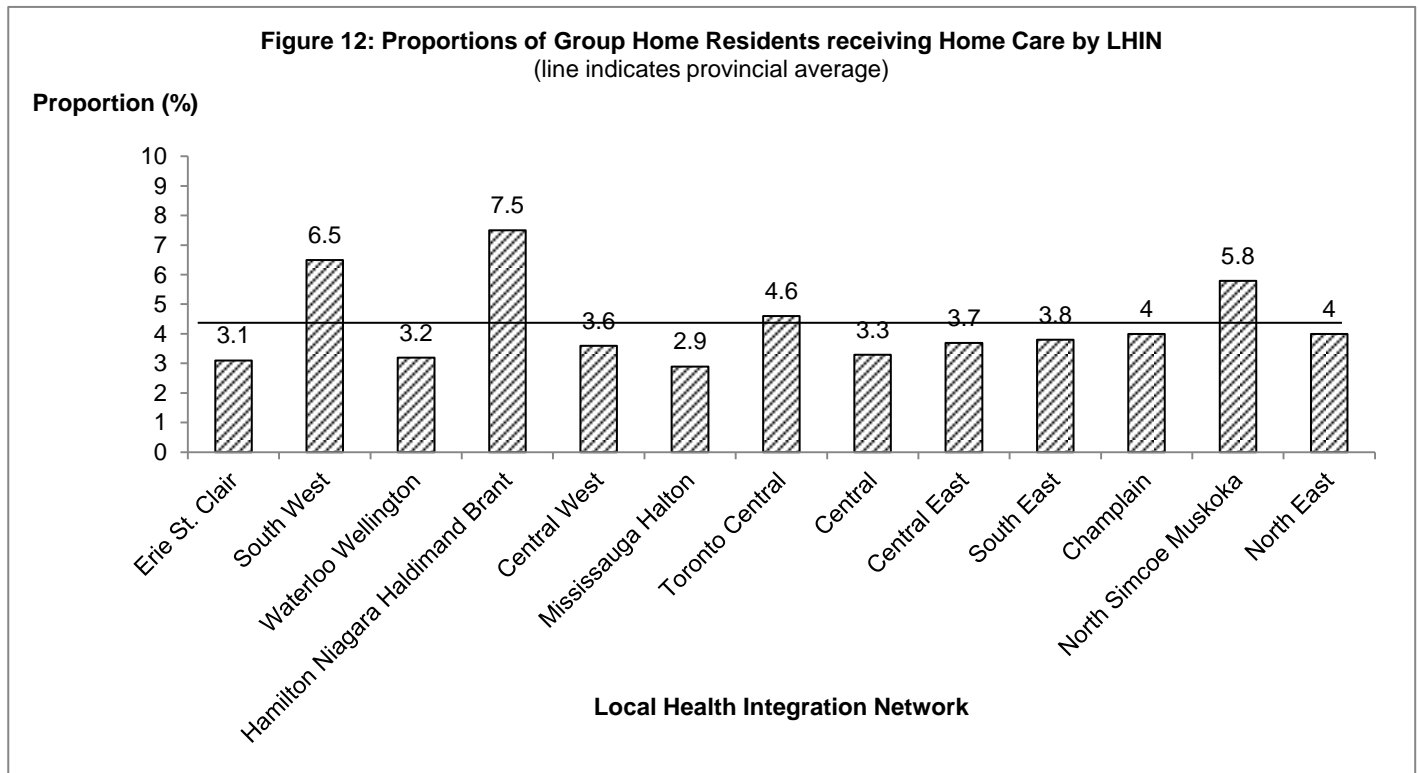
Personal characteristics

Of the 6,522 adults with developmental disabilities living in group homes, 4.5% received home care services. Table 2 describes the personal characteristics of these 292 adults with developmental disabilities with a home care assessment living in group homes, in relation to all 6,522 adults with developmental disabilities living in group homes. Just under 2% of those 18-44 used home care. This increased to 5% among those 45 to 64 years. Due to the way in which we identified individuals living in group homes, it is not possible to report on the proportion of group home residents 65 years or older who used home care. Women and persons residing in the poorest neighbourhoods were most likely to use home care, though no difference was observed based on rurality.

Table 2: Demographic Characteristics of Group Home Residents receiving Home Care

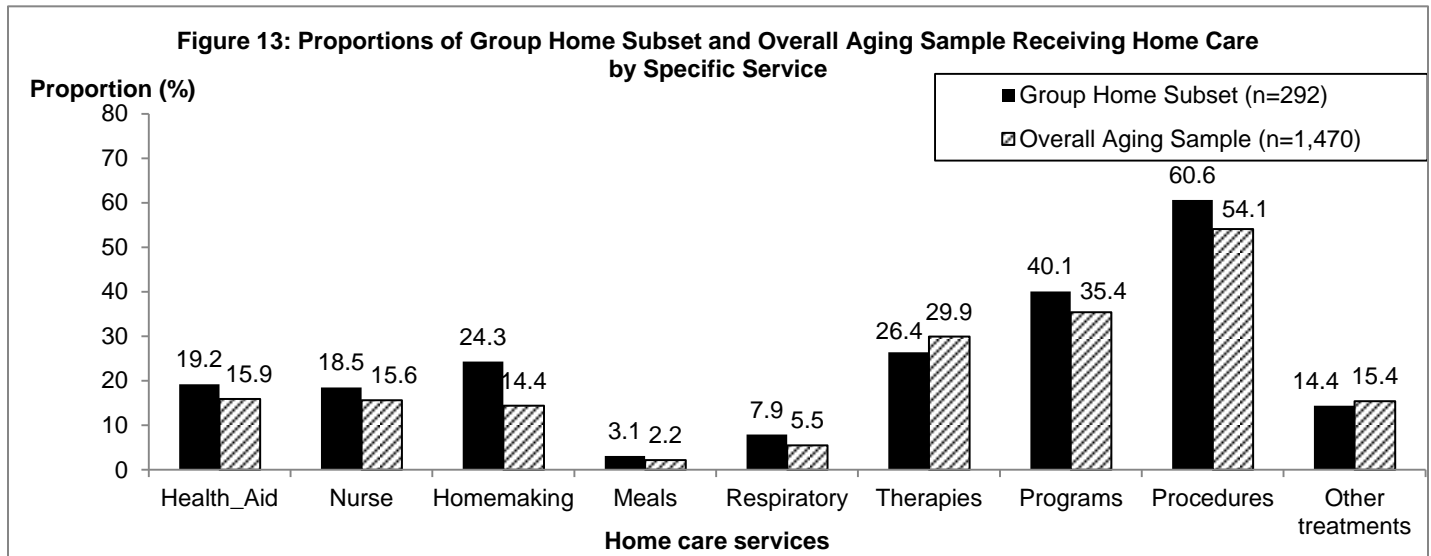
		Home Care Recipients (n=292)	All Group Home Residents (n=6,522)	%
Sex	Male	158	3,876	4.1
	Female	134	2,646	5.1
Income quintile (n=291)	1 (Low)	75	1,176	6.4
	2	65	1,222	5.3
	3	47	1,326	3.5
	4	64	1,450	4.4
	5 (High)	40	1,331	3.0
Type of Community	Urban	244	5,438	4.5
	Rural	48	1,084	4.4

Group home residents living in Hamilton Niagara Haldimand Brant, South West, and North Simcoe Muskoka regions were more likely to use home care, while those in Mississauga Halton, Erie St. Clair, Waterloo Wellington, and Central regions were least likely (Figure 12).



Formal services

In this section, formal service use and informal support received by the 292 adults with developmental disabilities living in group homes are compared to the overall sample of adults with developmental disabilities receiving home care services (n=1,470, which includes the 292 persons living in group homes). Those living in group homes were more likely to receive homemaking services and to have special procedures (e.g., daily nurse monitoring, medic alert bracelet or electronic security alert, skin treatment, special diet) provided in the home (see Figure 13). Those living in group homes were not more or less likely to use any of the other types of home care services considered.



Almost all adults with developmental disabilities receiving home care services had taken at least one medication in the last week (99.3% in group home subset and 96.7% in the overall aging sample). Adults with developmental disabilities residing in group homes were more likely to have taken psychotropic medications (71.6% vs. 63.3% in the overall cohort), and a greater number of medications (see Table 3). In fact, almost 60% (58.9%) of adults with developmental disabilities in group homes were taking nine or more medications, compared to just over 40% (42.3%) in the overall aging sample. Adults with developmental disabilities residing in group homes were more likely to have had their medications reviewed by a physician in the last six months.

Table 3: Medication Use and Oversight among Group Home Subset and Overall Aging Sample Receiving Home Care Services

	Group Home Subset (n=292)	Overall Aging Sample (n=1,470)
Psychotropic	209 (71.6%)	930 (63.3%)
Number Meds		
0	<=5	48 (3.3%)
1	<=5	71 (4.8%)
2	<=5	93 (6.3%)
3	7 (2.4%)	85 (5.8%)
4	26 (8.9%)	108 (7.3%)
5	17 (5.8%)	124 (8.4%)
6	18 (6.2%)	113 (7.7%)
7	22 (7.5%)	110 (7.5%)
8	21 (7.2%)	96 (6.5%)
9 or more	172 (58.9%)	622 (42.3%)
Mean ± SD	7.53 ± 2.17	6.38 ± 2.88
Medical oversight (180 days)	249 (85.3%)	1,139 (77.5%)

In the three months preceding the home care assessment, 37.9% of adults with developmental disabilities had been admitted to the hospital. The proportion was slightly lower among those living in group homes (34.2%). Similarly, about 20% of adults with developmental disabilities had visited the ER in the previous three months (20.9% in group home subset and 21.7% in the overall aging sample). A relatively small proportion of individuals had more than one hospital admission (4.1% in group home subset and 6.6% in the overall aging sample) or ER visit (5.5% in group home subset and 6.9% in the overall aging sample) within the 3-month period. See Table 4.

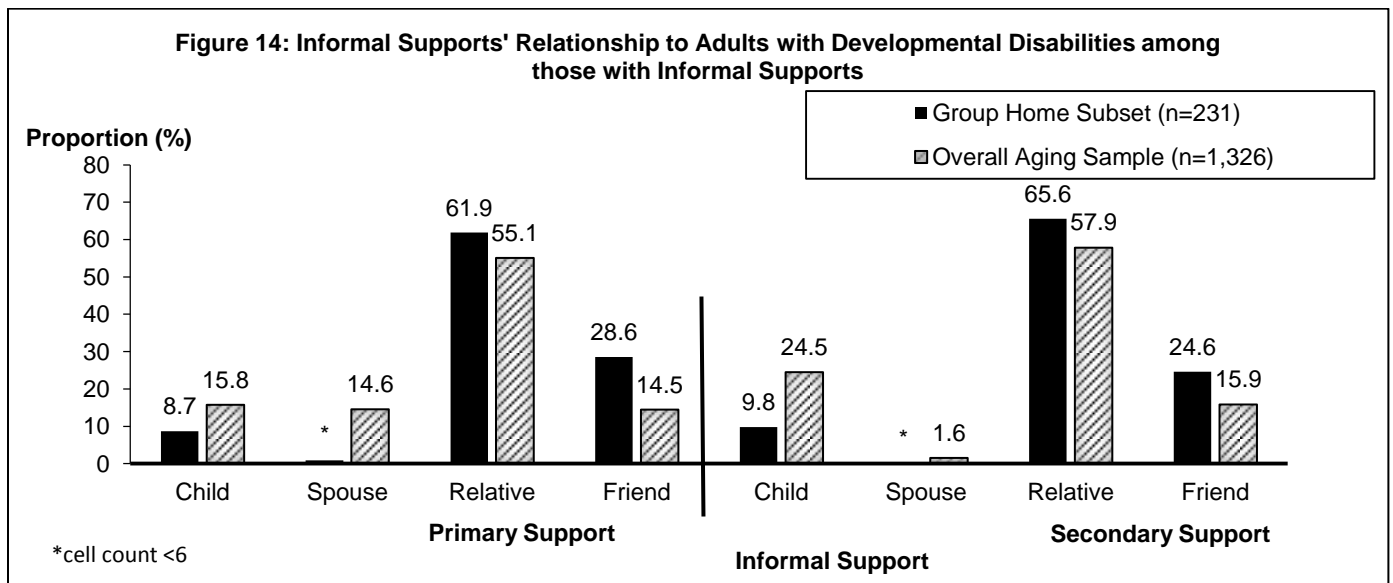
Table 4: Hospital use in the last 90 days among Group Home Subset and Overall Aging Sample Receiving Home Care Services

		Group Home Subset (n=292)	Overall Aging Sample (n=1,470)
Hospital Admission	0	192 (65.8%)	913 (62.1%)
	1	88 (30.1%)	460 (31.3%)
	2	10 (3.4%)	79 (5.4%)
	3 or more	<=5 (0.7%)	17 (1.2%)
	Mean (SD)	0.39 (0.59)	0.46 (0.67)
ER Visit 90	0	231 (79.1%)	1,151 (78.3%)
	1	45 (15.4%)	217 (14.8%)
	2	8 (2.7%)	50 (3.4%)
	3	<=5	24 (1.6%)
	4	<=5	14 (1.0%)
	5 or more	<=5	14 (1.0%)
	Mean (SD)	0.31 (0.77)	0.37 (0.94)

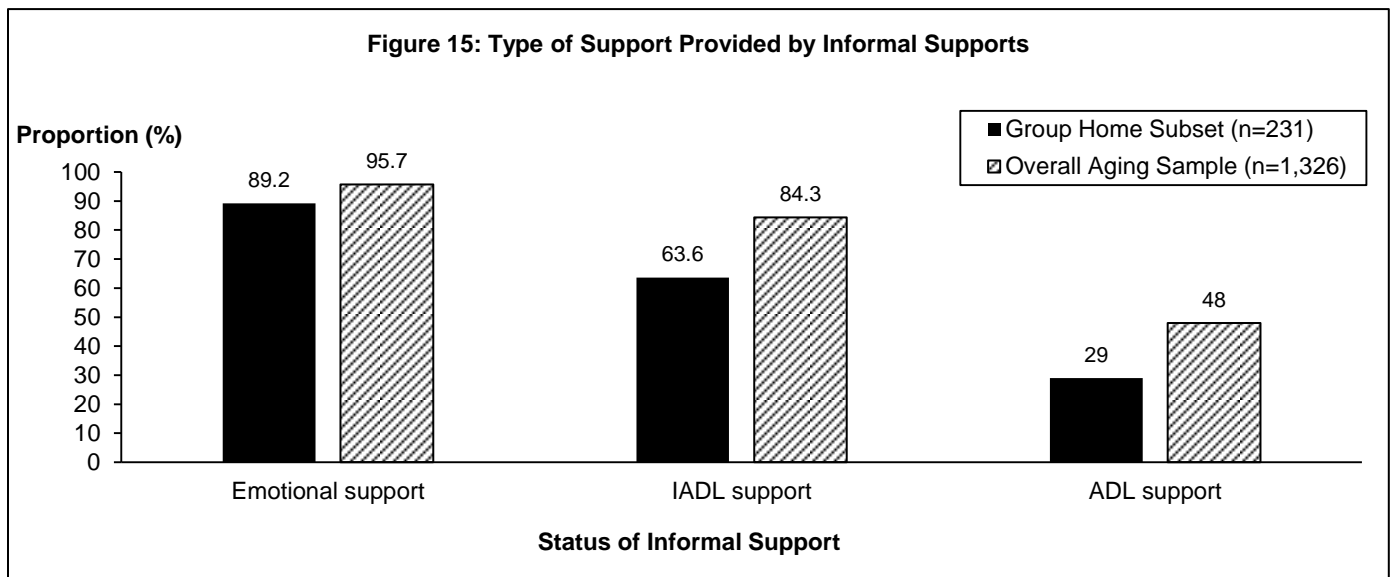
Informal support

The vast majority of adults with developmental disabilities receiving home care services had informal supports; that is one or more informal/unpaid caregiver. Specifically, these were present for 90.2% of the overall aging sample, and among 79.1% of the subset residing in group homes. Therefore, analyses in this section are restricted to those who have an informal support person present - i.e., 231 adults living in group homes, and 1,396 overall.

For just over half (55.1%) of adults with developmental disabilities receiving home care services who had informal supports available, a non-child or spouse relative (e.g., parent, sibling) acted as the primary informal support person; this was higher among those living in group homes (61.9%). In cases where adults also had a second informal support provider, these also tended to be non-child or spouse relatives. See Figure 14.



As shown in Figure 15, overall, the majority of adults with developmental disabilities assessed for home care received emotional support and support with instrumental activities of daily living (IADLs; e.g., meal preparation, housework, financial management, transportation) from their informal helper(s), whereas just under half received help with activities of daily living (ADLs; e.g., eating, dressing, bathing). This pattern was somewhat altered among adults with developmental disabilities living in group homes. A high proportion of those in group homes received emotional support from informal helper(s) (89.2%), but relatively fewer received support with IADLs (63.6%) and ADLs (29.0%).

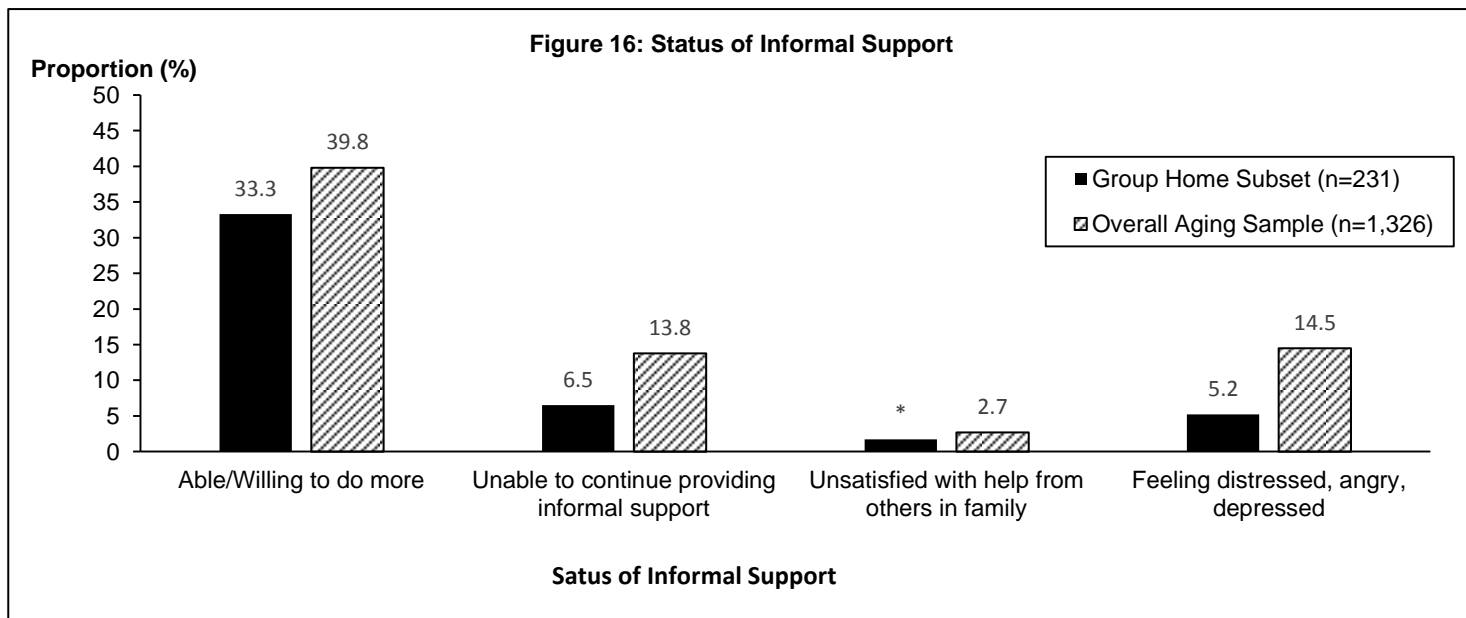


Overall adults with developmental disabilities who had informal caregivers received approximately 15 hours of informal support during the week, and almost 7 hours over the weekend, for a total of 22 hours of informal support in a 7-day period. Those living in group homes received fewer hours of informal support. See Table 5.

Table 5: Hours of Informal Support Provided to those who had Informal Supports

	Group Home Subset (n=231)	Overall Aging Cohort (n=1,326)
Average (SD) Weekday hours	10.8 (22.7)	15.4 (20.0)
Average (SD) Weekend hours	4.7 (9.1)	6.6 (10.3)
Average (SD) Total hours	15.5 (31.5)	22.0 (28.7)

As seen in Figure 16, approximately one third of informal helpers indicated both the ability and willingness to provide additional help if needed (39.8% overall, and 33.3% group home), while a non-trivial minority reported that they were unable to continue providing informal support (13.8% overall, and 6.5% group home). Among informal supports of adults with developmental disabilities living in group homes, very few reported feeling unsatisfied with the help that they were receiving from other family members (<=5) or expressed feelings of distress, anger, or depression (5.2%). The rate of dissatisfaction with the help received from other family members was also low in the overall sample (2.7%), though a higher proportion of informal supports expressed feelings distressed, angry, or depressed (14.5%).



Discussion and Further Research

Area 1

As it concerns aging, the service sector should prepare for an increase in individuals with developmental disabilities over the age of 64 in the immediate and short-term. These aging individuals are expected to have greater health care needs (including home care and long-term care) than the general population due to mental health and addiction problems and frailty.

Ongoing monitoring of the population (demographics) and its health care needs should be undertaken.

Area 2

The measure of frailty used makes a difference. Due to the differences between the full cohorts and the subsets of individuals who are assessed for home care and long-term care, it remains impossible to discern at what age adults with developmental disabilities are most likely to become frail. The use of the Frailty Marker in the overall cohort suggests that frailty associated with aging may be seen in adults with developmental disabilities as early as 40 years of age compared to 75 years in adults without developmental disabilities. This 35 year difference is consistent with recently reported gaps in life expectancy and age at death comparative statistics which also show such a difference between persons with and without developmental disabilities in Europe and Australia (Heslop *et al.*, 2014; Lavin *et al.*, 2006; Bittles *et al.*, 2002; Patja *et al.*, 2000).

More research is needed regarding the feasibility and utility of adapting frailty measures specific to developmental disabilities in clinical settings and for use when analyzing administrative data.

Area 3

Examination of home care data showed that older adults with developmental disabilities receive a variety of formal home care services; this was also true of persons residing in group homes. Women in group homes were more likely to receive home care services than men, as were persons living in poorer neighbourhoods (whether in a group home or elsewhere). There were differences in home care use among persons in group homes depending on the region - with the highest rates of home care use found in Hamilton Niagara Haldimand Norfolk Brant region and the lowest in Mississauga Halton region. Further investigation into regional policies related to use of home care services by persons living in group homes may be warranted.

In fact, there is a need to examine allocation of home care resources to persons in group home settings, given that the results showed that this group was more likely to receive homemaking services. This finding was surprising, as this is a role largely expected to be filled by service providers in the developmental services sector. Further investigation of the roles of health and developmental services providers in this context is warranted.

The results also showed that a greater proportion of home care recipients residing in group homes versus the overall group were taking psychotropic medication, as well as taking higher numbers of medications - approximately 60% of individuals in group homes were taking nine or more medications, compared to approximately 40% of home care recipients with developmental disabilities overall. There is evidence that medication usage is being closely monitored, however, as the vast majority had their medications as a whole reviewed by a physician in the last six months. The results also showed that, regardless of residential setting, about one third of home care recipients with developmental disabilities had been admitted to the hospital and about 20% had visited the ER in the previous three months.

The majority of home care recipients with developmental disabilities have an informal helper - this was true for approximately 80% of those in group homes and 90% overall. Among those who have informal support, this role is predominantly filled by a relative. The RAI-HC does not specify the nature of the relationship with the relative, and so it is not possible to determine the proportion of people being supported by a parent, sibling or other relative. This type of information would be particularly valuable on those not residing in a group home setting - i.e., to know how many people with developmental disabilities are being cared for by parents, especially in the older age groups. This information is important to understand the potential need for future planning, in the event that the parent is no longer able to support their aging child.

Over half of home care recipients with developmental disabilities were receiving emotional support and IADL support from their informal helper(s), regardless of residential setting. Support with ADLs was less common, and received by just under half of persons overall, and by about 30% of those in group homes. This was not altogether surprising, given that developmental services staff are likely to be providing ADL support in group home settings.

Overall, informal helpers reported relatively low rates of various indicators of caregiver distress; rates were even lower among informal helpers of people living in group home settings. In fact, approximately one third of informal helpers of persons in group homes said that they would be willing and able to provide additional support; this was true for 40% of informal helpers overall. That said, there is value in further work exploring rates of caregiver distress for persons not living in group home settings, as this could help to put into place policies and strategies that could prevent need for crisis support.

Conclusions

As it concerns aging, the service sector should prepare for an increase in individuals with developmental disabilities over the age of 64 in the immediate and short-term. These aging individuals are expected to have greater health care service needs than the general population due to medical issues, mental health and addiction problems, and frailty. In fact, this report showed that large proportions of persons with developmental disabilities were taking multiple medications - including psychotropic medication, had visited the ER, and had a hospital admission.

This report highlighted the types of formal home care services received by adults with developmental disabilities living in the community, as well as the informal support they receive. Findings suggest that there are regional differences in how aging adults with developmental disabilities are supported - with some regions having higher rates of home care use by persons with developmental disabilities than others. Further, it appears that persons residing in group home settings actually have higher rates of homemaking services, a service typically provided by the developmental services sector. This finding may help to inform resource planning and allocation in both the health and developmental services sectors, as well in the evaluation in the Aging at Home strategy province-wide.

The report also highlighted that the vast majority of adults with developmental disabilities receiving home care services are also receiving informal care, usually from a relative. Informal helpers provide emotional support, as well as support with activities of daily living (e.g., dressing, bathing, meal preparation, financial management), though the latter was less commonly received by persons with developmental disabilities living in group home settings. Rates of caregiver distress were relatively low, and a non-trivial minority (about 40% overall) of caregivers reported being both willing and able to provide more informal support if needed. There is value in monitoring the type and extent of informal support available to persons with developmental disabilities as it relates to the potential need for future planning. Close monitoring of caregiver status is also needed, especially among those caring for an individual outside of a group home setting (e.g., in their own home), as this could help to put into place policies and strategies that could prevent need for crisis support.

References

- Bittles, A. H., Petterson, B. A., Sullivan, S. G., Hussain, R., Glasson, E. J., & Montgomery, P. D. (2002). The influence of intellectual disability on life expectancy. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 57(7), M470-M472.
- Brehmer-Rinderer, B., Zeilinger, E. L., Radaljevic, A., & Weber, G. (2013). The Vienna Frailty Questionnaire for Persons with Intellectual Disabilities—Revised. *Research in developmental disabilities*, 34(6), 1958-1965.
- Bronskill, S. E., Carter, M. W., Costa, A. P., Esensoy, A. V., Gill, S. S., Gruneir, A., ... Wodchis, W. P. (2010). Aging in Ontario: an ICES chartbook of health service use by older adults - technical report. Toronto, ON: Institute for Clinical Evaluative Sciences.
- Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A. & Russ, L. (2014) The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet* 383, 9920, 889-895.
- Hirdes, J. P., Frijters, D. H., & Teare, G. F. (2003). The MDS_CHESS scale: a new measure to predict mortality in institutionalized older people. *Journal of the American Geriatrics Society*, 51, 96-100.
- Lavin, K. E., McGuire, B. E., & Hogan, M. J. (2006) Age at death of people with an intellectual disability in Ireland. *Journal of Intellectual Disabilities* 10, 2, 155-164.
- Lin, E., Selick, A., Balogh, R. S., Isaacs, B. J., Ouellette-Kuntz, H. M. J., Klein-Geltink, J. E., Cobigo, V., Wilton, A. S., & Lunskey, Y. (2013). Prevalence, Demographic and Disease Profiles (pp.20-40). In: Lunskey Y, Klein-Geltink JE, Yates EA, (Eds.). Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario. Toronto, ON: Institute for Clinical Evaluative Sciences.
- Nithianantharan, S. (2014). A conceptual model of frailty for individuals with intellectual disabilities. Unpublished undergraduate report available from H. Ouellette-Kuntz, Department of Public Health Sciences, Queen's University, Kingston, Ontario, K7L 3N6.
- Ouellette-Kuntz, H., & Wilkinson, A. (2013). Mortality patterns among individuals with intellectual disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, 10(2), 161.
- Ouellette-Kuntz, H., Coo, H., Lam, M., Breitenbach, M., Hennessey, P. E., Jackman, P. D., Lewis, S., Dewey, D., Bernier, F. P. & Chung, A. M. (2013). The changing prevalence of autism in three regions of Canada. *Journal of Autism and Developmental Disorders*. [DOI 10.1007/s10903-013-1856-1]
- Patja, K., Iivanainen, M., Vesala, H., Oksanen, H., & Ruoppila, I. (2000). Life-expectancy of people with intellectual disability: a 35-year follow up study. *Journal of Intellectual Disability Research* 44, 5, 591-599.

Schoufour, J. D., Mitnitski, A., Rockwood, K., Evenhuis, H. M., & Echteld, M. A. (2013). Development of a frailty index for older people with intellectual disabilities: results from the HA-ID study. *Research in Developmental Disabilities, 34*, 1541-1555.

Statistics Canada (2011). http://www12.statcan.gc.ca/census-recensement/2011/as-sa/98-311-x/2011003/fig/fig3_2-1-eng.cfm [accessed on 2July2014].

Appendix 1: Technical Definitions

Frailty: Two measures of frailty were considered:

1) *The Johns Hopkins University Adjusted Clinical Group (ACG) System*

This system classifies persons as frail if he/she has any one of 81 diagnostic codes (grouped into 11 clusters of medical issues) known to be highly associated with limited functioning among older adults (Bronskill *et al.*, 2010, p. 11). No information is available that specifies the diagnostic codes used in the ACG System.

2) *The Changes in Health, End Stage disease, Signs, and Symptoms (CHESS) scale*

This scale is embedded in the assessment instruments used as part of regular clinical practice in home care (i.e., the RAI-HC assessment) and long-term care (i.e., the RAI 2.0) settings in Ontario. The algorithm to derive the CHESS is based on the presence or absence of 9 issues related to frailty in older populations, including: cognitive decline; decline in performance of activities of daily living (ADLs, such as eating, dressing, bathing); shortness of breath; dehydration or insufficient fluid intake; edema; vomiting; weight loss; decrease in amount of fluid or food consumed; and instability of conditions (Hirdes, Frijters, & Teare, 2003). CHESS scale scores range between 0 and 4, where a score of 2 or more are used to indicate health instability. The CHESS has been shown to be a strong predictor of mortality, as well as of physician activity (e.g., visits, change orders), complex medical procedures, and pain among older adults (Hirdes *et al.*, 2003).

Group home: The following techniques were used to identify adults with developmental disabilities living in a Developmental Services residential setting - called 'Group Home' hereafter.

1) For adults aged 18-64 years, Group Home status was identified through the MCSS Service Delivery Model Technology (SDMT) data accommodation code (i.e., "DS Group Living (HRP)").

2) As information on the residential status of adults with developmental disabilities 65 years or more was not available in the SDMT data, an alternate way of identifying Group Home status was needed for older adults with developmental disabilities. The living arrangements of persons living in the community and receiving home care services are documented in the RAI-HC assessment instrument, which is used as part of regular clinical practice in all Community Care Access Centres (CCAC) in Ontario. Therefore, persons receiving home care services were considered to be living in a group home if they lived in a Group Home if they were coded as living in a "board and care/assisted living/group home" and were living in a "group setting with non-relatives".

Neighbourhood-level income: These quintiles are based on Statistics Canada Postal Code Conversion Files. Postal code information is taken from the Registered Persons Database.

Rurality: Rurality is based on having a postal code from the Registered Persons Database that corresponds to towns or municipalities outside the commuting zone of larger urban centers (with populations of 10,000 or more) based on Statistics Canada Postal Code Conversion Files.

Mental illness/substance use: These are individuals who have a diagnosed mental illness and/or substance abuse or addiction issue as previously defined by H-CARDD.

Additional Variables from the RAI-HC assessment

Hospital admission: The number of hospital admissions in the last 90 days.

ER visit: The number of Emergency Room visits in the last 90 days.

Emergent care: The number of unscheduled nursing, physician, or therapeutic visits to office or home in the last 90 days.

Number of medications: The number of medications taken in the last 7 days.

Presence of informal support: The person has informal support (i.e., an informal caregiver).

Relationship to primary informal support: This describes the person's relationship to his/her primary informal support (e.g., child, spouse, relative, friend).

Types of informal support received

- **Emotional support**
- **IADL support** - The person received support with Instrumental Activities of Daily Living (IADLs; e.g., meal preparation, housework, managing finances, transportation).
- **IADL support** - The person received support with Activities of Daily Living (ADLs; e.g., eating, dressing, bathing).

Informal support able/willing to do more - The person's informal support is able and willing to provide additional support, if needed.

Informal support unable to continue - The informal support person is unable to continue in caregiving activities (e.g., due to a decline in the health of the caregiver).

Informal support not satisfied - The informal support person is not satisfied with support received from family and friends.

Informal support distressed - The informal support person expresses feelings of distress, anger, or depression.

Hours of informal support provided

- **Weekday** - The sum of hours of informal support provided over 5 weekdays.
- **Weekend** - The sum of hours of informal support provided over 2 weekend days.
- **Total** - The sum of hours of informal support provided over 7 days (weekdays and weekend).



Health Care Access Research
and Developmental Disabilities

Health Care Access Research and Developmental Disabilities (H-CARDD)
Centre for Addiction and Mental Health
1001 Queen Street West
Toronto, Ontario, Canada M5V 2B4