

# Older Adults with Intellectual Disabilities in South Eastern Ontario

## A Brief Report

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in Intellectual Disabilities

Queen's University

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## **ABOUT SEO CURA in ID**

The South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA in ID) includes partners from across South Eastern Ontario as well as collaborators from other areas. The community partners are primarily developmental service sector agencies across the six county catchment area. The primary researchers are based at Queen's University in Kingston. A complete list of researchers and partners can be found on our website ([www.seocura.org](http://www.seocura.org)). Our vision is to augment the quality of life for individuals with intellectual disabilities and their families through enhanced inclusion, sense of belonging and support. Our goals are that research findings be used to inform policies and practices of service providers and government ministries and that the partnering experience inform future research areas and approaches.

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## **DISCLAIMER**

The views expressed in this study report are not necessarily the views of all SEO CURA in ID partners, researchers, collaborators or those of the funder.

## **CONTACT INFORMATION**

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## **Rationale**

This report provides a much needed profile of older adults with intellectual disabilities living in South Eastern Ontario. It may be helpful to other regions striving to understand the current and future needs of such older adults in their community.

## **Goal and Objectives**

The aim was to develop a descriptive profile of older adults with intellectual disabilities using available data provided by developmental service agencies in the six counties of South Eastern Ontario. Gender, living arrangements and geography [urban/rural] distributions are presented for older adults relative to younger adults with intellectual disabilities. While clinicians and researchers are in agreement that, as a group, adults with intellectual disabilities age prematurely, the age at which age-related changes are observed remains controversial. This report is therefore concerned in part with examining the impact of different age cut-offs on the prevalence of co-morbidities.

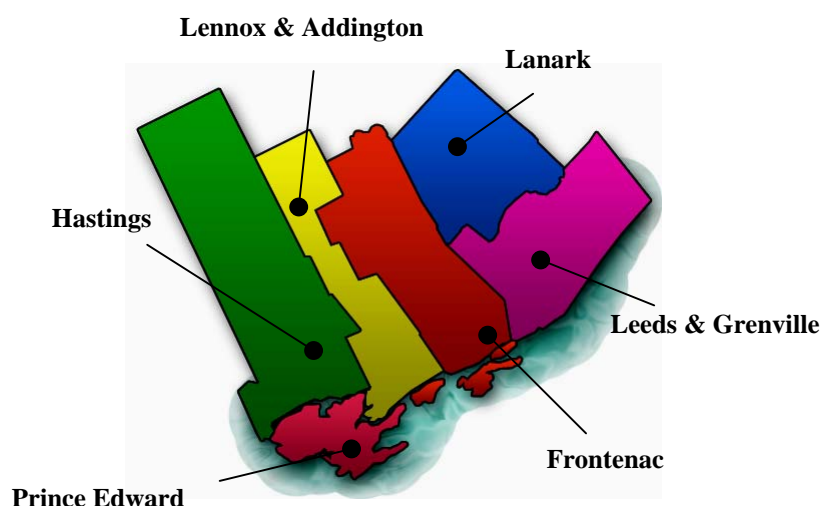
## **1.4 Methods**

### **1.4.1 Data Source**

The profile was derived from data captured in the 2006 update of the Geographic Registry in Intellectual Disabilities (GRID). This anonymized database captures information about the population across the six counties of South Eastern Ontario known to developmental service agencies as having an intellectual disability. GRID has evolved over a dozen years from a one-time survey of individuals known to developmental service agencies in Lanark County (1994) to an annually updated agency survey including data received from 36 service providers across South Eastern Ontario who are partners in SEO CURA in ID. It is estimated that 4000 individuals with ID will at some point in their lives become known to the partner-agencies as they or their families make requests for services. The data included in GRID is as reported by agency staff and/or from the client's file. No independent assessments of the clients are made. A copy of the data collection form can be found in Appendix A.

Geographically speaking, South Eastern Ontario (see Figure 1) is predominantly rural. Frontenac is the most densely populated county with a population density of 39.2 persons per square kilometre. The county of Lennox and Addington has the lowest population density of 14.6 persons per square kilometre. The region has a total population of just over half a million (n=503,668; Statistics Canada, 2006 Census)

Figure 1: The Six Counties of South Eastern Ontario



### 1.4.2 Data Analysis

All client data collected for GRID are stored in electronic form within an Access database. Data processing and analysis for this project were conducted using Excel, Access and SPSS (Version 14.0). The aging profile is described according to client clinical and demographic characteristics (including geography and living arrangement).

Information relevant to identifying co-morbid conditions is recorded on the GRID data collection form in two distinct ways. Agency staff can check 'P' next to a listed condition to indicate it is present; that is it affects the client. Agency staff may also specify 'other conditions which have a significant impact on daily living'. Since many conditions and behaviours were recorded on the GRID data collection form in the space provided to specify other conditions, a query was

performed in Access to identify conditions or behaviours specified for each client. Conditions and behaviours were initially coded using the International Classification of Disease, Ninth Revision (ICD-9). The data was then cleaned to update any missing or incorrect information. After these steps were completed, the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) served as a basis for assigning conditions as psychiatric and/or behavioural. Two new variables were created to capture those conditions or behaviours with the ability to be categorized as a psychiatric disorder or problem behaviour including those specified as well as the instances where agency staff checked 'P' to indicate presence of such conditions.

A second query was performed to identify the following for each client: age, gender, postal code, county and living arrangement. Using SPSS (Version 14), conditions and behaviours data were merged with demographic data using Client ID as the common variable. The merged data was then ready for analysis. Cross-tabulations were performed to examine the relationships between age and the following other client characteristics: gender, urban center, county and living arrangement. Odds ratios were calculated to identify the strength of the observed relationships across variable categories.

## **1.5 Results**

### **1.5.1 Sample Characteristics**

A total of 2323 adults with intellectual disabilities were identified in the GRID database. Adults were considered as anyone 18 years of age or older. The ages ranged from 18 to 85 years (mean= 41.2 years; standard deviation=15.1 years). There were 1287 men (55%) and 1036 women (45%). The most common living arrangements were living with parents or siblings (31%), followed by living in a group home (28%) and living alone (17%).

Using postal code information for classification, most of the group (60%) are living in a rural area with the remainder (40%) living in or near urban centres (areas of Greater Kingston, Belleville or Brockville). Over half of the adults with intellectual disabilities (53%) live in either the counties of Frontenac (28%) or Hastings (25%); which is consistent with the census population distribution (Frontenac: 28.5%; Hasting: 25.9%).

Nine hundred and fifty one (40.9%) were 45 years or older. They are compared to those 18 to 44 in Table 1.

Table 1: Comparison of “Younger” and “Older” Adults with Intellectual Disability in South Eastern Ontario (n=2323)

		18-44 years (n=1372)	45 years and older (n=951)
Gender	Female	603 (44.0%)	433 (45.5%)
	Male	769 (56.0%)	518 (54.5%)
Living Arrangement	Alone	203 (14.8%)	196 (20.6%)
	Group Home	299 (21.8%)	348 (36.6%)
	Parents/Siblings	612 (44.6%)	115 (12.1%)
	Host/Foster Family	103 (7.5%)	120 (12.6%)
	Room/Housemates	31 (2.3%)	22 (2.3%)
	Seniors Residence	4 (0.3%)	13 (1.4%)
	Spouse/Children	77 (5.6%)	65 (6.8%)
	Hostel/Room and Board	15 (1.1%)	19 (2.0%)
	Correctional/Health Facility	15 (1.1%)	49(5.2%)
	Other*/ Not Reported	12 (0.9%)	4 (0.4%)
	Geography	Rural Area	800 (58.3%)
Urban Center		572 (41.7%)	355 (37.3%)
County	Frontenac, Lennox & Addington	504 (36.7%)	353 (37.1%)
	Lanark, Leeds & Grenville	417 (30.4%)	286 (30.1%)
	Hastings, Prince Edward	451 (32.9%)	312 (32.8%)
Common Conditions (not mutually exclusive)	Dual diagnosis**	530 (38.6%)	356 (37.4%)
	Communication disorder	421 (30.7%)	285 (30.0%)
	Seizure disorder	255 (18.6%)	162 (17.0%)
	Vision problems	291 (21.2%)	210 (22.1%)
	Hearing problems	131 (9.5%)	108 (11.4%)
	Mobility problems**	---	25.8%

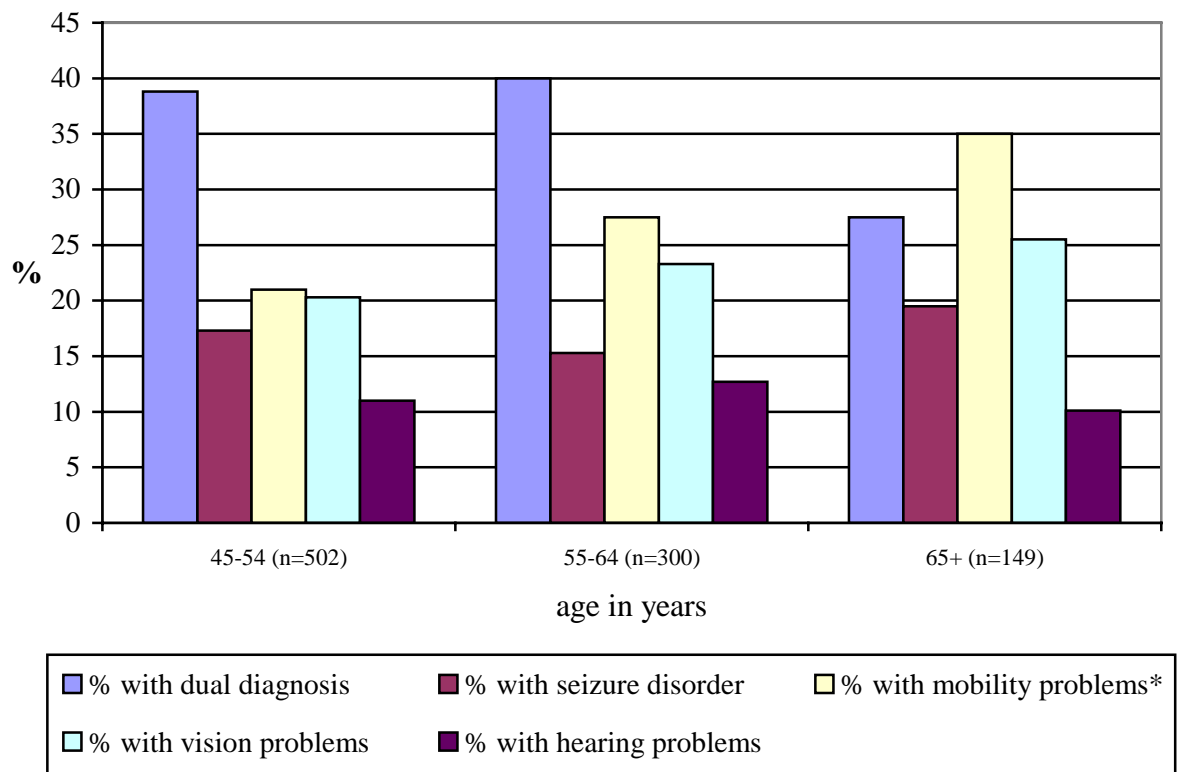
\*Includes: Alternative to women’s shelter, homeless, non-profit housing, private living arrangement and residential school.

\*\*‘psychiatric conditions’ and/or ‘problem behaviours’

\*\*\*As per RMI score <12 (likely to have substantial difficulty independently participating in activities inside and outside the house without notable compensatory strategies and equipment. Based on GRID sample of 128 adults with ID reported in Cleaver, S. (2007). Physical Mobility and Aging in Intellectual Disabilities. MSc Thesis in the Dept. of Community Health & Epidemiology, Queen’s University, Kingston, Ontario.

The following figure examines the distribution of demographic and clinical variables of “older” adults across age categories.

Figure 1: Proportion affected by co-morbidities across three older age groups of adults with intellectual disabilities in South Eastern Ontario



\*mobility study samples were of 57, 51 and 20 across the respective age groups

## **1.6 Summary of Findings**

Many individuals with intellectual disabilities in South Eastern Ontario are living well into their 50s, 60s and beyond. The higher proportion of males found in the young age groups persists beyond age 45. The pattern of living arrangements for adults over the age of 45 is different from that of their younger counterparts. Those in the older group are most likely to live in group homes (36.6%) while the younger adults are most likely to live with parents or siblings (44.6%). The proportion who live in correctional or health facilities is much higher among the older group (5.2% versus 11.%). A slightly higher proportion of older adults live in rural areas compared to the younger group (62.7% versus 58.3%). The older adults with intellectual disabilities appear to be proportionately distributed across our three sub-regions (bi-county areas). While co-morbidities/common conditions are as likely to be reported in younger adults as in those 45 years and over, as Figure 1 shows, the proportions affected by mobility and vision problems increase with age. The effects of aging on the occurrence of other conditions such as dual diagnosis, seizure disorder and hearing problems is not demonstrated by the data available.

**Limitations:** Since the current study only includes adults with intellectual disabilities known to developmental service agencies, it is expected that a number of individuals with mild intellectual disabilities will be missed. The data available from GRID used for analysis in this study has been obtained from developmental service agency staff who may or may not have consulted the client's file when completing the data collection form. Of particular note is the lack of specificity in the information provided to GRID to describe common conditions. No attempt has been made to confirm the clinical information provided. Given the challenges in diagnosing some conditions in adults with intellectual disabilities (such as mental illness and behaviour disorders) and the potential for diagnostic overshadowing (such as attributing symptoms indicative of sensory impairment to the intellectual disability), it is suspected that the data includes both false positive as well as false negatives.