



Health Care Access Research  
and Developmental Disabilities



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# ***High Cost Users of Health Care Among Adults with Developmental Disabilities: Summary Report***

**Applied Health Research Question Series**

**Health System Performance Research Network**

**Health Care Access Research and Developmental  
Disabilities Program**

**Report Prepared by: Y. Lunsky, C. de Oliveira, D.  
Wilton & W. P. Wodchis**

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This report is available at the HSPRN website, <http://hsprn.ca>, and the H-CARDD website, <http://hcardd.ca>.

For inquiries, comments, and corrections please email [info@hsprn.ca](mailto:info@hsprn.ca) or [hcardd@camh.ca](mailto:hcardd@camh.ca).

## **Context**

The [Health Care Access Research and Developmental Disabilities Program](#) (H-CARDD) has studied the health service use of over 66,000 adults with developmental disabilities and demonstrated that they have more complex health profiles and are more likely to use hospital based services than adults without developmental disabilities. However, no research has been conducted to date on the costs of such health care services. At the same time, the [Health Systems Policy Research Network](#) (HSPRN) has focused on health care costs of various vulnerable groups in Ontario, but has not targeted developmental disabilities specifically.

In recent years, the Ministry of Health and Long-Term Care (MOHLTC), the Local Health Integration Networks (LHINs), and Community Health Links have worked to identify patients with multiple complex chronic conditions and mental health issues who use a significant amount of health care resources. These patients are sometimes referred to as “high cost users” or high needs patients and are the primary focus or target population of Health Links.

Thus far, those with developmental disabilities have not been a focus of Health Links. This may be in part because there is no information on how common it is for adults with developmental disabilities to be high cost users of health care. If, in fact, it is determined that a subgroup of them are high cost users, health care resources targeted toward this group could be integrated into the Health Link settings, especially now that the MOHLTC is working to “advance” the Health Links model. This determination would also make it clear that there is a need for closer collaboration and partnership between Health Links and the Developmental Services sector, which has not occurred to date.

This project builds upon previous work conducted by the H-CARDD program and by HSPRN for the inter-ministerial provincial committee focused on complex needs. The prior project explored what is known about individuals with complex needs, but did not focus on the costs of health care specifically for those with developmental disabilities.

## **Project Goal**

In this project, we were interested in determining the proportion of adults with developmental disabilities from within the H-CARDD cohort who might fall within in the target population of Health Links, based on total health care costs. We aimed to describe the demographic and clinical profiles of high cost users with developmental disabilities, compared to other adults with developmental disabilities within the H-CARDD cohort with lower health care costs.

## **Methods**

The H-CARDD team worked jointly with the HSPRN to study “high cost users” with developmental disabilities (DD) FY-2009/10 and 2010/11. We computed health care costs for the 2009/10 fiscal year for all adults within the H-CARDD cohort, and then categorized them with cost cut offs determined for the broader Ontario adult population under age 65.

## Key Findings

Major Findings were:

1. Overall, approximately 20% of adults with DD fell in the “top 5%” category of health care users, using costs for the general population age 18 to 64. This would suggest that these adults are disproportionately represented in the high cost users category.
2. Individuals in the “top 5%” were older and more likely to be women than lower cost users. The majority were receiving ODSP. They tended to be living in similar neighbourhood income categories to lower cost users.
3. Individuals in the “top 5%” were more likely to have a range of chronic diseases and had overall higher morbidity than lower cost users. Individuals with moderate morbidity were equally likely to be in the low and high cost user groups.
4. The majority of individuals in the high cost users group were incurring outpatient, hospitalization, and medication costs.
5. There was some stability in who was a high cost user one year later.

A break down on the number and percentage of health care users with developmental disabilities falling into each “high cost category” by LHIN is attached in Table 1 (Page 5).

## Conclusions and Implications

This study has allowed us to examine, for the first time, the overall health care costs of adults with developmental disabilities in our province. Based on our findings, health-based initiatives such as Health Links, which focus on individuals with complex needs, would be relevant to a substantial subgroup of adults with developmental disabilities (as many as one in five), who incur significant health care costs.

We believe that this information is relevant to Ontario policy makers concerned about health care delivery and developmental disabilities. It may also be relevant to the LHINs and Health Links in the province as they plan who they will target in Health Links moving forward.

To learn more about the health care needs of adults with developmental disabilities in Ontario, please visit [www.hcardd.ca](http://www.hcardd.ca).

Useful clinical tools to better meet the health needs of the developmental disabilities population can also be found on the H-CARDD website.

Table 1. Distribution of high cost users with developmental disabilities by LHIN in 2009/10.

<i>LHIN</i>	Total N	Top 10% N	Percentage	Top 5% N	Percentage	Top 1% N	Percentage
<i>Erie St. Clair</i>	4057	1634	40.3%	926	22.8%	311	7.7%
<i>South West</i>	6242	2277	36.5%	1373	22.0%	535	8.6%
<i>Waterloo Wellington</i>	3267	1048	32.1%	609	18.6%	203	6.2%
<i>Hamilton Niagara Haldimand Brant</i>	9158	3411	37.2%	2027	22.1%	665	7.3%
<i>Central West</i>	2321	761	32.8%	449	19.3%	166	7.2%
<i>Mississauga Halton</i>	3054	971	31.8%	559	18.3%	227	7.4%
<i>Toronto Central</i>	4575	1694	37.0%	1064	23.2%	421	9.2%
<i>Central</i>	5321	1887	35.5%	1077	20.2%	334	6.2%
<i>Central East</i>	6702	2383	35.5%	1404	20.9%	499	6.7%
<i>South East</i>	4610	1646	35.7%	948	20.6%	308	6.7%
<i>Champlain</i>	6875	2652	38.6%	1564	22.7%	553	8.0%
<i>North Simcoe Muskoka</i>	2780	1008	36.2%	595	21.4%	243	8.7%
<i>North East</i>	5194	1901	36.6%	1131	21.8%	428	8.2%
<i>North West</i>	1828	619	33.9%	382	20.9%	159	8.7%