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SUMMARY

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ICES

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Disclaimer

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Issue

Building on previous work by the Health Care Access Research and Developmental Disabilities (H-CARDD) Program, which showed that Ontario adults with developmental disabilities have poorer physical and mental health and use more health care services than other adults, this report takes an integrated, cross-sectoral approach to further study this heterogeneous and vulnerable population.

We followed a cohort of 64,699 Ontario residents with developmental disabilities who were between 19 and 65 years of age in 2010 for a six-year period between April 2010 and March 2016 and compared this group to adults without developmental disabilities for five health and health care outcomes. We examined the five outcomes by age, sex and the wealth or poverty of the neighbourhood where people lived, as well as by the type of developmental disability they had.

This work was done collaboratively by a group of scientists, clinicians, advocates and policy-makers. Our findings have relevance in Ontario and other jurisdictions where there is interest in improving the health care and health status of individuals with developmental disabilities.

Study goals

- To describe how adults with developmental disabilities differ from other adults with regard to five important health and health care outcomes: 30-day repeat emergency department visits, 30-day repeat hospitalizations, alternate level of care, long-term care and premature mortality.

- To describe these five outcomes for three subgroups of individuals with developmental disabilities: adults with Down syndrome, adults with autism, and adults with developmental disabilities and a mental health and/or addictions diagnosis.

- To synthesize patterns across all findings and develop outcome-specific and overarching recommendations that can enhance policy, practice and intersectoral planning.

Key findings

Compared to adults without developmental disabilities, adults with developmental disabilities consistently fared worse across all five outcomes. This pattern held true regardless of age, sex, the wealth or poverty of the neighbourhood where they lived or the kind of developmental disability they had.

Among adults with developmental disabilities, the pattern of poor outcomes differed depending on the type of developmental disability.

30-Day repeat emergency department visits

- Adults with developmental disabilities, compared to adults without developmental disabilities, were more likely to have at least one 30-day repeat emergency department visit in the six-year study period (34.5% vs. 19.6%). This pattern was observed for all age groups and both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived.

- Among adults with developmental disabilities, those with a mental health and/or addictions diagnosis had a particularly high rate of repeat emergency department visits (42.8%).

Recommendations to reduce 30-day repeat emergency department visits:

- Develop and update cross-sector crisis, safety or care plans for all individuals with developmental disabilities following their initial emergency department visit and assess the impact of these plans on preventing repeat visits.

- Include adults with developmental disabilities and partners from the developmental disabilities sector in the current Ontario quality review processes for patients with repeat emergency department visits.

30-Day repeat hospitalizations

- Adults with developmental disabilities, compared to adults without developmental disabilities, were more likely to be readmitted to hospital within 30 days of their initial discharge in the six-year study period (7.4% vs. 2.3%). This pattern was observed for all age groups and both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived.
- Among those with developmental disabilities, persons with a mental health and/or addictions diagnosis had a particularly high rate of repeat hospitalizations (11.0%).

Recommendations to reduce 30-day repeat hospitalizations:

- Because patients with developmental disabilities are at high risk for readmission, flag them upon admission, link that flag to specific actions and provide them with enhanced cross-sector supports to transition out of hospital.
- Address the unique needs of patients with developmental disabilities in broader health care system initiatives to reduce rehospitalizations, such as patient-oriented discharge summaries.

Alternate level of care

- Adults with developmental disabilities, compared to adults without developmental disabilities, were more likely to have at least one alternate level of care day in hospital in the six-year study period (4.6% vs. 0.7%). (Alternate level of care is defined as care administered to patients who remain in hospital but are ready for discharge.) This pattern was observed for all age groups and both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived. Among the age groups, the adults with the highest rate of alternate level of care were those with developmental disabilities who were 50 to 65 years old (9.7%).
- Among adults with developmental disabilities, those with a mental health and/or addictions diagnosis had a particularly high rate of alternate level of care days (6.1%).

Recommendations to reduce alternate level of care:

- Proactively begin discharge planning upon admission with the person with a developmental disability, his or her caregivers, and his or her health and social service partners.
- Incorporate recognition of developmental disabilities into the broader system of alternate level of care solutions and tailor accordingly.

Long-term care

- Adults with developmental disabilities, compared to adults without developmental disabilities, were more likely to spend at least one day in long-term care in the six-year study period (3.5% vs. 0.2%). This pattern was observed for all age groups and both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived. Among age groups, adults with the highest rate of long-term care use were those with developmental disabilities who were 50 to 65 years old (9.6%).
- Among those with developmental disabilities, adults with Down syndrome had a particularly high rate of long-term care use (8.2%).

Recommendations to address long-term care issues:

- Because the health of people with developmental disabilities declines at an earlier age, planning should begin early to ensure that supports are in place to allow them to age at home appropriately and to delay entry to long-term care.
- Within long-term care settings, supports tailored to the needs of those with developmental disabilities should be available, including the provision of staff with enhanced knowledge and training about developmental disabilities.

Premature mortality

- Adults with developmental disabilities, compared to adults without developmental disabilities, were more likely to experience premature mortality in the six-year study period (6.1% vs. 1.6%). (Premature mortality is defined as death before age 75.) This pattern was observed for all age groups and both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived. Among the age groups, the adults with the highest rate of early death were those with developmental disabilities who were 50 to 65 years old (14.6%).
- Among those with developmental disabilities, adults with Down syndrome had a particularly high rate of premature mortality (12.3%).

Recommendations to address premature mortality:

- Conduct developmental disability mortality reviews, as is being done in other countries, to identify contributors to premature deaths with a focus on preventable causes.
- Design and monitor interventions based on these reviews.

Cross-outcome implications and guiding principles

Adults with developmental disabilities were consistently disadvantaged for every outcome examined in this report. This reinforces other research demonstrating that these adults are a complex and highly vulnerable population and supports the recommendation that they require multifaceted solutions that address a range of health care outcomes. In addition, these solutions need to be tailored to the needs of specific developmental disability subgroups in order to increase their impact and relevance.

Many of the recommendations for the five outcomes overlap, pointing to the need to take a broader system perspective when considering interventions. Otherwise, as has been shown in other jurisdictions, solutions risk being implemented in an uncoordinated and siloed fashion. We recommend that four system-wide guiding principles be kept in mind when considering and implementing solutions. It should be noted that these principles are consistent with the 2006 *United Nations Convention on the Rights of Persons with Disabilities*, the *Ontario Human Rights Code* and the 2005 *Accessibility for Ontarians with Disabilities Act*.

1. Follow the rule of *Nothing about us without us*. People with disabilities and their families and supporters should be fully and meaningfully involved in the development of policies, programs and services that affect their lives.
2. A range of proactive supports and health care services should be provided in the community that are appropriate for and accommodate the specific needs of people with developmental disabilities.
3. Appropriate supports and health care services should be available and accessible in emergency department, hospital and long-term care settings.
4. When adults with developmental disabilities transition between different health care services or between health care and community settings, these transitions should be planned, well-coordinated and seamless.

Recommending how these guiding principles should be operationalized and by whom is beyond the scope of this report and should be determined by collaborative decision-making among all stakeholders. Our experience and the literature suggest that implementing these principles will be difficult unless the following key ingredients are present:

- A fully integrated, province-wide infrastructure that provides routine and timely information to
  - Providers regarding which patients have a developmental disability (by flagging or documenting in a health record), what their needs are and what gaps in care and support need to be addressed; and

  - Administrators, planners and policy-makers so they can monitor and evaluate the performance of existing supports and services. In addition, new initiatives should be subjected to small but well-designed and time-sensitive evaluations.

- Education for all stakeholders about their respective roles and responsibilities in creating and maintaining good health for people with developmental disabilities; and
- Availability of individuals with specialized expertise in developmental disability health care, when required.

H-CARDD

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

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