

Researchers call for health-care changes to help adults with developmental disabilities

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Adults with developmental disabilities such as autism and Down syndrome are having a harder time accessing health care even though they have more health issues than people without developmental disabilities, according to research done at the Institute for Clinical Evaluative Sciences (ICES) and the Centre for Addiction and Mental Health (CAMH).

"This group of individuals is a silent minority in the [health care](#) system, but now instead of just relying on anecdotal evidence, we finally have the big picture on their health and the [health services](#) that they use," says Yona Lunskey, lead author of the Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario.

The atlas, the largest study of its kind, found there are over 66,000 [adults](#) with developmental disabilities under age 65 in Ontario. Adults with developmental disabilities live in poorer neighbourhoods and have higher rates of physical and [mental health problems](#) than other Ontario adults. They receive multiple medications for these [health issues](#), which are not always well monitored. While they are as likely to see their family physician as other adults, they are more likely to visit emergency departments and to be hospitalized.

"These individuals don't get the same level of preventive care, such as cancer screening and not all of their chronic health issues are managed as well as they should be. In general, their care is not consistent with what health-care guidelines recommend for adults with developmental

disabilities," says Lunsky, a clinician scientist at CAMH, an adjunct scientist at ICES and director of the Health Care Access Research and Developmental Disabilities (H-CARDD) research program.

"Although the level of care was good during emergencies, there was a recurring mantra of 'patch her up and send her out until the next time' ... We felt then, as we do now, that there needs to be a better process that connects hospitals, caregivers, family doctors and patients with a focus on long-term intervention, thereby reducing the need for emergency hospitalization," says Roger Oxenham, father of a young adult with developmental disabilities.

Researchers are recommending strategies to enhance the overall health and wellbeing of individuals with developmental disabilities. They include:

- Enabling [primary care](#) providers to more easily offer guideline-recommended care
- Addressing the broader health system issues and pathways to care, and
- Making people with developmental disabilities and their families and paid staff active partners in care, giving them the tools they need.

The H-CARDD program has two projects underway to improve health outcomes for adults with [developmental disabilities](#): the Primary care project with family health teams and the Emergency care project.

Lunsky will be speaking at Health and Wellbeing in Developmental Disabilities: Engaging Health Care Professionals conference in Toronto on November 12 and 13.

Provided by Centre for Addiction and Mental Health

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