

Good primary lowers ED use for those with intellectual and developmental disabilities

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One in three adults with intellectual and developmental disabilities (IDD) visit the emergency department annually but effective primary care could reduce these numbers, suggests a new study led by St. Michael's Hospital and the Institute for Clinical Evaluative Sciences (ICES).

"For populations with IDD, the emergency department can be a frustrating and overwhelming place," said Dr. Anna Durbin, scientist at the Li Ka Shing Knowledge Institute of St. Michael's and lead author of the study. "Many people with IDD—about 88 per cent—are already accessing some form of primary care and it's a great way to reach them. What can we do during these visits to prevent potentially difficult experiences in the emergency room?"

Diagnoses of IDD include Down syndrome, fetal alcohol spectrum disorder, autism and other pervasive developmental disorders, all presenting with adaptive behaviour deficits. Using administrative health databases combined with disability income support records, the research team studied the data of 66,464 adults aged 18-64 in Ontario with IDD, and compared the numbers to a random sample of about two million Ontarians without IDD. Researchers found that those with IDD were almost 1.5 times more likely to visit the emergency department. The study also found that the proportion of emergency department visits due to psychiatric issues was at least double for <u>patients</u> with IDD than for those without IDD.

Greater continuity of primary care, which means not only accessing



services in the community but also continuing to see the same care provider from appointment to appointment, was associated with a lower probability of future emergency department visits. This was the case in both populations but the relationship was more pronounced in those with IDD.

For Dr. Bill Sullivan, a family physician in the St. Michael's Academic Family Health Team, these findings solidify what he has seen in frontline practice with patients with IDD. Though Dr. Sullivan has been involved in other studies about patients with IDD and the development of guidelines to improve their primary care, he was not involved this study.

"Patients with IDD may have trouble communicating and articulating their symptoms and their story to health-care providers," he said. "Things that are fairly easy for us to diagnose because we know the patient can be difficult to sort out for staff in the <u>emergency department</u> who are unfamiliar with him or her. It's important not only to have the same health team collaborating with patients, but also to focus on preventive care. That way, we can screen and address health issues and provide support before symptoms present or escalate to the point of needing emergency care."

Though Dr. Sullivan and his team have made strides in the treatment of patients with IDD by developing comprehensive care guidelines, gaps still exist. These gaps are in part due to the nature of IDD, said Dr. Yona Lunsky, Senior Scientist at CAMH and senior author of this study.

"These are often invisible disabilities," said Dr. Lunsky, who is also the director of the Health Care Access Research and Developmental Disabilities (H-CARDD) Program at CAMH. "It's up to us in the health-care world to be willing to take the time to notice them and adjust our care accordingly."



"Until we take a deep dive into this patient group, we won't have a roadmap," said Dr. Durbin. "It's only recently that researchers have started looking at <u>emergency</u>-based care for adults with IDD."

Provided by St. Michael's Hospital

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