

Individuals with intellectual and developmental disabilities (IDD) represent one of the most complex and poorly understood patient groups. They are also the most expensive to serve.

Perhaps the most challenging setting to serve these patients is in the emergency department (ED). In the ED, access to patient history is limited, the time to develop relationships between patients and doctors is limited, and patients and caregivers are unprepared and in a state of crisis. ED staff feel ill trained to manage patients with IDD. Similarly, people with IDD (Lunsky & Gracey, 2009) and their caregivers (Weiss, et al., 2009) report dissatisfaction with their ED experience.

To better understand the challenges experienced in the ED by persons with IDD, first we conducted a qualitative study where we spoke with families, direct care staff and people with IDD who visited the ED, along with staff from 6 Toronto based hospitals.

Findings from this work led to The Crisis Study (*CIHR operating grant FRN #79539*)¹ which took place from 2007 to 2010. A transdisciplinary team of health systems researchers and clinicians in collaboration with 34 developmental disability and mental health agencies across 3 regions of Ontario studied psychiatric crises experienced by 751 Ontario adults with IDD.

Together we studied:

- (1) why do some people go to the emergency department in crisis when others manage outside of hospital?
- (2) what takes place during emergency department visits?
- (3) why do some visits result in hospital admission but others do not?
- (4) the lived experience of people with IDD and their caregivers in crisis.

This study filled an important knowledge gap about contributors to emergencies in this vulnerable, marginalized population, and identified several problematic issues that contribute to inadequate care. The study was augmented by additional research on health services and IDD as part of a CIHR New Investigator Award awarded to Dr. Lunsky.

¹ Lunsky, Y., Strike, C., Dawe, I., Durbin, J., Elliott, D., Jones, J., Burge, P., Morris, S., Cairney, J., & Goering, P. (2007-2010). Managing psychiatric crises in individuals with intellectual disabilities. Canadian Institutes of Health Research

KEY FINDINGS FROM THIS PROGRAM OF RESEARCH

#1: Persons with IDD have very high rates of ED use

- 50% of all adults with IDD visited the ED in a two year period
- they were 3 to 4 times more likely to be frequent visitors compared to those without IDD.

The first emergency visit is an OPPORTUNITY to better prepare patients with IDD for the next visit, should it need to occur.

#2: In addition to clinical need, lack of access to prevention and management supports predict why people with IDD visit EDs

- 20% of crises studied led to an emergency visit, and that those who visited the ED previously were *nine times more likely* to visit again when in crisis.
- Contributors were not just clinical need variables but also systemic variables like clinical and community supports.

People with IDD need primary care, crisis prevention and management plans and access to appropriate community support and resources.

#3: Treatment in EDs is inadequate for many individuals and service users report dissatisfaction with treatment received.

- 29% of visits resulted in hospital admission.
- Even though individuals with IDD have difficulty reporting their clinical history, hospital staff failed to record any consultation with caregivers more than half of the time.
- Most of the individuals who were not admitted to hospital did not have specific follow-up appointments or services set up by the hospital. In part, this may be because hospitals lack information on appropriate resources for this population, particularly for emotional concerns.
- Rates of satisfaction with hospital visits were lower for psychiatric emergencies than for medical emergencies.

Any staff training in hospital needs to include clinicians and staff outside of psychiatry. In addition to focusing on how to conduct optimal assessments, hospitals need strategies to connect patients with community based IDD resources.

To learn more about findings from the study including a link to a 90 minute presentation on study findings and implications:

http://www.ontario.cmha.ca/mental_health_notes_story.asp?cID=922962

Papers that might be of interest....

Are adults with developmental disabilities more likely to visit EDs

Access the abstract at

<http://medconnect.com.sg/tabid/100/ct9/c209707/Are-adults-with-developmental-disabilities-more-likely-to-visit-EDs-/Default.aspx>

Read an excerpt about the implications of study findings of this study at

http://www.camh.net/News_events/News_releases_and_media_advisories_and_backgrounds/DD_ER_ICES_CAMH.html

QUALITATIVE STUDIES DESCRIBING THE HOSPITAL EXPERIENCE

The reported experience of four women with intellectual disabilities receiving emergency psychiatric services in Canada: A qualitative study.

Access the abstract at

<http://jid.sagepub.com/content/13/2/87.abstract>

**Emergency psychiatric services for individuals with intellectual disabilities:
Perspectives of hospital staff.**

Access entire article at

www.iod.unh.edu/pdf/START/Emergency%20Room-Psychiatric.pdf

**Emergency psychiatric services for individuals with intellectual disabilities:
Caregivers' Perspectives**

Access the abstract at

<http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3148.2008.00468.x/abstract>

PAPERS FROM THE CRISIS STUDY

**Predictors of emergency department visits by persons with intellectual disability
experiencing a psychiatric crisis.**

Access abstract at

<http://ap.psychiatryonline.org/Article.aspx?ArticleID=307914>

**Life events and emergency department visits in response to crisis in individuals with
intellectual disabilities**

Access the abstract at

<http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2788.2011.01417.x/abstract>

Emergency psychiatric service use by individuals with intellectual disabilities living with family

Access full article at

<http://www.tandfonline.com/doi/full/10.1080/19315864.2011.597540>

The brief family distress scale: A measure of crisis in caregivers of individuals with autism spectrum disorders

Access a preview of the article at

<http://www.springerlink.com/content/e3hp7723m1h57721/>

Individuals with intellectual disabilities who live with family and experience psychiatric crisis: Who uses the emergency department and who stays home?

Access entire article at

<http://www.tandfonline.com/doi/full/10.1080/19315864.2011.599013>

Antipsychotic medication prescription patterns in adults with developmental disabilities who have experienced psychiatric crisis

Access abstract at

<http://www.sciencedirect.com/science/article/pii/S0891422211003064>

USEFUL GUIDELINES AND TOOLS TO MANAGE IN HOSPITAL AND TO PREVENT HOSPITALIZATIONS

Primary care of adults with developmental disabilities. Canadian consensus guidelines

Access full article at

<http://www.cfp.ca/content/57/5/541.full>

Guidelines for managing the client with intellectual disability in the Emergency Room.

Access full article at

http://www.camh.net/Publications/Resources_for_Professionals/guidelines_manageclient_emerg2003.pdf