



Welcome to Volume 6 (Spring) 2013 of the Research Digest

The Southern Network of Specialized Care publishes the Research Digest twice a year to share community-based research with the people who support those who have intellectual/developmental disabilities (ID) and/or dual diagnosis. Each of the six (6) articles in this volume summarizes research regarding visits to the Emergency Department (ED) across several Ontario-based hospitals people who have ID and/or dual diagnosis. These findings intersect with your experience and how they may inform your practice in the future.

The common themes are from the research findings of Ontario-based researcher, Dr. Yona Lunsky, and her collaborating partners. Dr. Lunsky completed her Ph.D. in clinical psychology at The Ohio State University, specializing in the area of mental health in developmental disorders.

She is now an Associate Professor at the University of Toronto in the Department of Psychiatry, the Research Section Head in the Dual Diagnosis Program at the Centre for Addiction and Mental Health and an Adjunct Scientist at the Institute for Clinical Evaluative Sciences. She has written over 100 research papers and book chapters on ID and mental health.



Megan Primeau, Dr. Yona Lunsky, Beth Anne Currie and Michelle Dermenjian

We look forward to hearing how we can continue to make this publication relevant for you and invite you to the **6th annual Research Forum, September 23rd, 2013** – where local researchers and their work will be highlighted throughout the day.

Summary of Key Findings in Volume 6:

1. Hospital personnel (doctors & nurses) require more education about working with people who have dual diagnosis. Help to inform and educate with good preparation before each visit.
2. Hospital personnel report that it is difficult to get accurate information from the patient or the caregiver. Be prepared with accurate information. Develop a Crisis Guideline that can be brought to the ED along with a summary of important information, e.g., medications, allergies, communication style, likes and dislikes.
3. ED's are busy and stressful with wait times ranging from 5-12 hours, which can cause anxiety for a person with IDD or dual diagnosis. Request a quiet place for the person (and their family) to wait if possible.
4. ED staff may not consider a medical problem that is contributing to the challenging behaviour you are seeing. If the behaviour exhibited by the person is atypical, advocate for exploration of medical issues as a possible cause for their behaviour before proceeding.
5. ED staff report feeling unprepared to provide the necessary care when the ED is used as a last resort. Support staff can assist by calling the ED prior to find out what to bring along.
6. Hospital staff are not always aware of the community supports available for people with dual diagnosis and find it challenging to get connected to these agencies. This highlights a need for better service coordination between hospital and the community.

Here are some interesting summaries about Research for you to Read!!!

Emergency Psychiatric Service Use by Individuals with Intellectual Disabilities Living with Family. Yona Lunsky, Ami Tint, Suzanne Robinson, Alin Khodaverdian, and Christine Kaskulski. Journal of Mental Health Research in Intellectual Disabilities. Volume 4, Issue 3, 172-185, 2011.

The researchers conducted this study to explore and describe the experiences of 20 people with intellectual disabilities (ID) who experienced a psychiatric crisis and made 44 visits to 10 different Emergency Departments over the period of one year.

The researchers connected with 34 agencies across Ontario who provide support services for people with ID, and who were able to identify those individuals who had visited an Emergency Department for a psychiatric crisis within a time frame. Hospital documentation was reviewed (hospital charts and crisis forms completed by the agency in preparation for the ED) including the initial complaint, relevant diagnosis, assessment and treatment, hospital disposition and any additional recommendations.

Seven of the 44 individuals made more than one visit during the study period and three of the Individuals visited the ED more than five times. The number of recorded visits for individuals ranged from 1 to 10 visits.

Outcomes of the ED visits:

- ◆ Physical aggression reported in 39% of visits;
- ◆ Psychiatric symptoms in 23% of visits;
- ◆ Suicidal behaviour or ideation in 16% of visits;

- ◆ 7 of the 44 visits 16% involved restraints;
- ◆ 6 of the 44 or 14% of the individuals were discharged with a prescription for new medication or a medication change. **NOTE:** Prescribing new or changing medication is cautioned against in the Primary Care Guidelines for persons with ID;

- ◆ An individual with ID was more likely to have been seen by a psychiatrist if a caregiver was present and part of the assessment process;
- ◆ 43% of the visits resulted in psychiatric admission and the persons with ID were discharged in 57% of the visits;

- ◆ 35% of the visits involving physical aggression but did not result in admission; and,
- ◆ 14 out of 25 or 56% of individuals were sent home with no recorded follow up appointment or resources for future crisis. This addresses the need for more community services that families and caregivers can access as opposed to using the ED.

The researchers caution that the findings of this study are exploratory and should be considered preliminary.



Emergency Psychiatric Services for Individuals with Intellectual Disabilities: Caregiver's Perspectives. Jonathan A. Weiss, Yona Lunsky, Carolyn Gracey, Maaike Canrinus & Susan Morris. Journal for Applied Research in Intellectual Disabilities, 2009, 22, 354-362.

The purpose of the study was to understand the experience of caregivers and adults with ID and mental health issues, as they related to making visits to the Emergency Department (ED) .

The researchers conducted focus groups (people are invited to group interviews) of caregivers within the Greater Toronto area that were composed of family members, unpaid caregivers and community agency staff (paid caregivers). Focus groups were one hour in length and used the same set of six questions for each group.

There was strong agreement among the focus group participants about their key reasons for emergency department visits and their concerns and challenges at the ED. The main reason for visiting the ED was often the result of extremely challenging behaviour, i.e., aggression towards others and property, self-injury, or suicidal behaviour.

The main concern reflected by the caregivers was about being unable to keep all parties safe with group members reporting that visiting the ED was the only option at times. Paid caregivers reported that repeat visits to the ED with the same individuals are an attempt to access crisis services for the individual. Their responses indicate a lack of appropriate and available crisis mental health services in the community that can effectively meet the needs of a person with ID.

Groups highlighted their ED experiences as follows:

- ◆ the “lack of transparency” about the ED process;
- ◆ the long wait times;
- ◆ the lack of a secure waiting area;
- ◆ the lack of assistance while waiting;
- ◆ the “lack of sufficient knowledge, training, and experience from hospital staff with regard to people with ID.”;
- ◆ that ED staff that are unfamiliar with ID and assume that mental health and behavioural issues are related to the person's ID and “fail to see the potential psychiatric or medical reasons underlying a change in behaviour” (diagnostic overshadowing);
- ◆ that ED staff may not have the extra time needed for accurate assessment for people with ID;
- ◆ an over-reliance on medication to suppress problem behaviours without adequately assessing the possible cause;
- ◆ that negative attitudes and comments were directed towards the person with ID who is in crisis or there was a lack of attention given to the person; and,
- ◆ that caregivers reported feeling they were quickly dismissed and their knowledge and experience was not considered or acted upon in the assessment or treatment for the person with ID.



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The Reported Experience of Four Women with Intellectual Disabilities who are receiving Emergency Psychiatric Services in Canada.

Yona Lunsky and Carolyn Gracey. Journal of Intellectual Disabilities, 2009, Volume 13 (2) 87-98.

The researcher's goal was to review the experiences of women who have Intellectual Disabilities (ID) who have visited the Emergency Department (ED) when experiencing a psychiatric crisis between 2003 and 2005. The researchers also spoke to hospital staff.

Participants were asked to discuss their experiences in the ED, specifically to share any challenges they encountered, the comfort level of the hospital staff, and to make suggestions on how the ED process could be improved.

The research participants shared the following primary challenges:

- * Hospital staff feels poorly equipped to provide the necessary care to individuals with ID in the ED (Lunsky, 2008);
- * Hospital staff lack knowledge and training regarding patients with ID;
- * Few community and respite services for caregivers to for respite and help to deal with crisis;
- * Hospital staff has an over-reliance on caregivers;
- * Negative attitudes of hospital staff;
- * Issues regarding diagnostic overshadowing – failure to recognize mental illness when a person has an ID; and,
- * Medication—over prescribing, inappropriately prescribing, and poor monitoring and follow-up.

From the perspective of the women, they reflected:

- * A lack of respect from hospital staff about their rights, forced testing and treatment, rude attitudes, referring to people by their diagnosis, being judged for the challenges they face;
- * Issue of consent (not being asked to give their consent);
- * Medication administration challenges; and,
- * Concerns about being physically restrained and given medication without trying something else first.

NOTE: A positive experience at the ED was reported by one woman who felt both the respect and concern of the hospital staff when they needed to employ a physical restraint.

The woman also made some suggestions for improvement:

- * Don't power trip;
- * Don't try to control them;
- * Speak to them respectfully;
- * Don't abuse or hit them;
- * Don't judge people for their issues;
- * Be more patient; and,
- * Treat them like you would want to be treated;



Dual Diagnosis: A National Study of Psychiatric Hospitalization Patterns of People with Developmental Disability. Yona Lunsky and Rob Balogh. Canadian Journal of Psychiatry, Vol 55, 11, November 2011, pages 721 – 728.

The purpose of this research was to compare hospitalization patterns for those with and without an intellectual disability, when a mental health condition was the basis for their hospital admission. The comparisons came from database that is administered by the Canadian Institute for Health Information between April (2005)-March (2006).

Key Findings:

- * Of the 8,376 hospital admissions of people with an intellectual disability, 41.5% (3,478) were for psychiatric reasons
- * Most admissions involved people between the ages of 15 and 24 years.
- * There were slightly more males than females hospitalized
- * Primary diagnosis was schizophrenia or psychotic disorders, followed by mood disorders
- * Generally speaking, the length of the hospital stays were relatively similar to those who were hospitalized without an intellectual disability

NOTE: Individuals with an intellectual disability are likely to be hospitalized 2 or 3 times more compared to the general population. Why? It may suggest that their initial hospitalization was not specialized or intensive enough to resolve the issue.

Conclusions:

- * It is important to understand the hospitalization patterns for people with an intellectual disability and a mental health concern, so that appropriate resources can be allocated to this group.
- * People with intellectual disabilities in Canada are to access and receive mainstream medical services, yet medical professionals receive little specialized training to treat this population.
- * Access to specialized community mental health services may not be adequate enough to prevent the person from going to the hospital.



Here are some interesting summaries about Research for you to Read!!!

Individuals with Intellectual Disabilities Who Live with Family and Experience Psychiatric Crisis: Who Uses the Emergency Department and Who Stays Home. Jonathan A. Weiss, Maggie Slusarczyk and Yona Lunsky. Journal of Mental Health Research in Intellectual Disabilities, 2011, 4: 158-171.

This study was conducted to explore the reasons why families with members who have Intellectual Disability (ID) are using the Emergency Department (ED).

The researchers looked at 192 people and their families, along with the type of clinical signals that were associated with the crisis, any preventative planning that could have been effective including community-based services and supports. A psychiatric crisis was defined as “an acute disturbance of thought, mood, behaviour, or social relations that requires an immediate intervention as defined by the individual family or the community.” (Allen, Forster, Zealberg, & Currier, 2002, p. 8).

The research team reviewed reports of crisis for individuals over a 2 year time period to determine what factors influenced whether or not someone accessed the Emergency Department with a psychiatric crisis.

The study noted no significant differences in age, gender or minority status between those who chose to go to the ED and those who stayed home. Of interest however, was that those who used the ED were more likely to have a borderline or mild intellectual disability.

Compared to people who did NOT access the ED, those who did were more likely to:

- * have experienced significantly more negative life events;
- * had more historical risk factors;
- * a greater number of psychiatric diagnoses, including anxiety; and,
- * were more inclined to not be involved in meaningful day time activities.

The results indicated that the presence of an autism spectrum disorder did not influence whether or not someone accessed the ED. However, the presence of psychiatric issues including likelihood of self-injury and the presence of physical aggression emerged as the more frequent types of crisis experience across groups.

Emergency Psychiatric Services for Individuals with Intellectual Disabilities: Perspectives of Hospital Staff. Yona Lunsky, Carolyn Gracey and Sara Gelfand. Intellectual and Developmental Disabilities, Vol 46, 6: 446-455, December 2008.

The purpose of this study was to “identify clinical and systemic issues surrounding emergency psychiatry services for people with intellectual disabilities, from the perspective of hospital staff.” The study defines a psychiatric emergency as “any behaviour that cannot be dealt with as rapidly as needed by ordinary mental health, social service, or criminal justice system help in a community” (Hillard, 1994, p. 541).



The researchers conducted focus groups from six, high volume general hospitals in the Toronto area. They were chosen specifically because they have frequent ED (Emergency Department) visits from people who have ID. Forty four staff participated in the focus groups which included psychiatrists, psychiatry residents, nurses, social workers, and other crisis workers, allied health professionals, and managers.

The focus groups were asked the following questions:

1. What are the most common presenting problems of people who have ID?
2. What is your comfort level treating patients who have ID?
3. What are the common challenges encountered in the ED?
4. What supports and services are required by hospital staff?

The following themes were identified: lack of knowledge, training, support, and resources for both hospital staff and caregivers. Focus groups indicated the ED receives one to two visits per week by people who have an ID.

The primary reasons are due to:

- ⇒ Physical aggression
- ⇒ Burn out of caregivers/respites/last resort
- ⇒ Housing crisis and lack of ability to place
- ⇒ Food/social contact

When asked what made them the most uncomfortable about these visits, hospital staff reported that the use of restraints to manage behaviour created the most discomfort.

They reported the main challenges during the ED visit were:

- * A lack of information about potential services for the person;
- * A lack of knowledge and experience with this population;
- * The lack of understanding on the part of the patient or caregiver about procedures and limitations of the hospitals;
- * The lack of background information provided by the patient/caregivers and the length of time it takes to gather relevant information;
- * Inability to find respite placement on discharge;
- * A difficulty communicating with other service providers and caregivers effectively
- * Caregiver burnout; and,
- * The complexity of medical issues in the individuals with ID and the long wait times to go through medical clearance

For psychiatrists with little experience in treating a person who has an intellectual disability, the researchers found that:

- ⇒ The patient's communication problems, attention difficulties, memory impairments, and challenging behaviour are often intensified in a stressful and unfamiliar environment;
- ⇒ Frequently patients have been prescribed multiple psychotropic medications that can play a role in triggering or escalating the crisis; and,
- ⇒ The person's capacity to provide consent to treatment is often unclear.

The following recommendations from the focus group may prevent unnecessary visits to the ED:

1. Need more caregiver support with a greater emphasis on respite in the community;
2. Need communication with an MH case manager or management team in the community;
3. Need caregiver training about coming to ED; and,
4. Need rapid on-site treatment.



Disclaimer:

Neither the Southern Network of Specialized Care nor its Advisory Committee endorses the views and recommendations discussed in this publication.

The views are those of the authors and the journals in which these are published.

We accept no responsibility for the views discussed, as this publication is for informational purposes only.

Next Steps:

The Southern Network of Specialized Care with the SNSC Advisory Committee are pleased to support opportunities for linking with researchers in the field of Dual Diagnosis. Please consider joining us at the annual Southern Network Research Forum Days that occurs each fall. If you would like more information on the annual Research Forum, please contact the SNSC Research Facilitator:

Beth Anne Currie at bethannecurrie@sympatico.ca

Also, please find links to research publications, research funding, research applications and more on our website at www.community-networks.ca

If you would like to discuss a research opportunity or a program evaluation project, please email Beth Anne Currie at bethannecurrie@sympatico.ca



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