Integrated Knowledge Translation: What does it mean and why is it relevant to dual diagnosis research?

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Risperidone, haloperidol, and placebo in the treatment of aggressive challenging behaviour in patients with intellectual disability: a randomised controlled trial

Peter Tyrer, Patricia C Oliver-Africano, Zed Ahmed, Nick Bouras, Sherva Cooray, Shoumitro Deb, Declan Murphy, Monica Hare, Michael Meade, Ben Reece, Kofi Kramo, Sabyasachi Bhaumik, David Harley, Adrienne Regan, David Thomas, Bharti Rao, Bernard North, Joseph Eliahou,

**Interpretation** Antipsychotic drugs should no longer be regarded as an acceptable routine treatment for aggressive challenging behaviour in people with intellectual disability.

Flexible doses of haloperidol (a typical, first-generation antipsychotic drug), risperidone (an atypical, second-generation antipsychotic), and placebo, in the treatment of this behaviour.
Diabetes Prevalence Among Persons With Serious Mental Illness and Developmental Disability

Yona Lunsky, Ph.D.
Elizabeth Lin, Ph.D.
Rob Balogh, Ph.D.
Julie Klein-Geltink, M.H.Sc.

The prevention and treatment of diabetes among individuals with serious mental illness has been a recent focus in part because of the reportedly direct relationship between antipsychotics and metabolic syndrome. Adults with developmental disability are also at high risk of diabetes because of their sedentary lifestyle, cognitive impairments, and deficits in adaptive behavior and are less likely than other vulnerable populations to receive appropriate diabetes care (1). Some individuals with developmental disability also have serious mental illness. Whether they are at higher risk of diabetes than those with either serious mental illness or developmental disability alone has not been studied.

Identified records of all physician billings and hospital visits made by Ontario residents. The four groups and those with treated diabetes were identified using ICD-9 and ICD-10 codes and the Ontario Diabetes Database, respectively.

Compared with the rate in the general population, diabetes rates were higher in the three groups (severe mental illness, developmental disability, and the combined group) (Table 1). When age and sex were controlled for, the odds of having diabetes were 1.78 times higher (95% confidence interval [CI]=1.75–1.82) among those with severe mental illness and 1.84 times higher (CI=1.75–1.94) among those with developmental disability, compared with those without serious illness or disability.

Further research is required to determine what role they might play. Our data suggest that increased attention to persons in the combined group by monitoring their clinical symptoms and functioning levels and devising better ways to help them and their families manage their treatment would be useful, pending more definitive answers.

Acknowledgments and disclosures

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Clinical and Benefit–Cost Outcomes of Teaching a Mindfulness-Based Procedure to Adult Offenders With Intellectual Disabilities

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The effects of a mindfulness-based procedure, called Meditation on the Soles of the Feet, were evaluated as a cognitive-behavioral intervention for physical aggression in 6 offenders with mild intellectual disabilities. They were taught a simple meditation technique that required them to shift their attention and awareness from the precursors of aggression to the soles of their feet, a neutral point on their body. Results showed that physical and verbal aggression decreased substantially, no Stat medication or physical restraint was required, and there were no staff or peer injuries. Benefit–cost analysis of lost days of work and cost of medical and rehabilitation because of injury caused by these individuals in both the 12 months prior to and following mindfulness-based training showed a 95.7% reduction in costs. This study suggests that this procedure may be a clinically effective and cost-effective method of enabling adult offenders with intellectual disabilities to control their aggression.

Keywords: mindfulness; Meditation on the Soles of the Feet; physical aggression; Street and institutionalized offenders with intellectual disability
Knowledge to action strategies

www.youtube.com/watch?v=osUwukXSd0k
Knowledge Transfer

- “a systematic approach to capture, collect and share tacit knowledge in order for transfer it to become explicit knowledge. By doing so, this process allows for individuals and/or organizations to access and utilize essential information, which previously was known intrinsically to only one or a small group of people.” Government of Alberta (http://www.pao.gov.ab.ca/learning/knowledge/transferguide/index.html accessed Jan 24, 2006).
Knowledge Transfer

- End of grant KT
- Integrated KT
Integrated KT is similar to making and keeping friends

- Who are the friends we want to have?
- How do we make friends?
- How do we keep friends?
- What is so great about old friends?
Who are the friends I wanted to make?

- Clinicians
- Developmental sector service providers
- Direct staff
- Families
- People with disabilities
- Policy makers
- Researchers in other areas
- The general public
Choose your friends carefully

- You can’t become a good friend to everyone all at once

- START WHERE IT MAKES THE MOST SENSE
“Mom, you don’t make friends with people -- you friend them.”
Making new friends

- You need to talk about things they are interested in

- FIND OUT WHAT RESEARCH TOPICS ARE IMPORTANT
Making new friends

- FITTING IN:
  - You need to talk in a way they understand
  - Don’t be a show off!
  - LISTEN

THINK ABOUT **HOW** YOU HAVE THE DISCUSSIONS ON WHAT IS IMPORTANT TO BE STUDIED
Making friends in different contexts

- Different groups think different things are important.
- LISTEN TO EACH GROUP
- The “social rules” are different wherever you go
- Learn those rules
Keeping friends

- Make sure you are true to your word
- Maintain balance, reciprocity
- Keep listening
- Give credit when it is due
- Be open to new experiences and to shifting directions
- Be able to admit you were wrong
- Keep in touch
ED FOCUS GROUPS PROJECT

- Lack of knowledge
- Medication and restraint
- Respect and compassion
- Lack of resources in hospital and community

(Lunsky, Gracey & Gelfand, 2008)
(Weiss, Lunsky, Gracey, Canrinus, & Morris, 2009)
(Lunsky & Gracey, 2009)
- We needed to understand more about the unique characteristics of those who visit the ED in crisis
- 2007 we launched a 3 year study on crisis and ID
GOAL OF PROJECT

- To follow as many people with ID as possible to see:
  1. **Who** has a crisis
  2. **Which** crises lead to ED visits
  3. **What** happens in the ED
Participating Agencies

**Toronto** – 21 (Community Living Etobicoke, Community Living Central Toronto, Community Living North York, Community Living Scarborough, CORE, COTA, DDRS, Griffin Centre, Kerry’s Place, L’Arche, Mary’s Centre, Meta, Muki Baum, New Leaf, Operation Springboard, Reena, Salvation Army, Surex Community Services, Surrey Place, Vita Community Living, Woodgreen Community Services, York Community Services)

**Peel** – 5 (Community Living Mississauga, Brampton Caledon Community Living, Peel Crisis Capacity Network, Central West Specialized Developmental Services, Peel CAMH)

**Kingston** – 5 (Ongwanada, Community Living Kingston, DDCOT, MHT, APSW)
Participating Hospitals

- **Toronto** (CAMH, Humber River Regional, Mt. Sinai, North York General, Rouge Valley Health System, St. Josephs Health Centre, St. Michaels, Sunnybrook Health Science Centre, The Scarborough Hospital, Toronto East General, Toronto General, Toronto Western)

- **Peel** (Credit Valley, William Osler Health Centre, Peel Memorial, Trillium)

- **Kingston** (Kingston General Hospital, Hotel Dieu)
BREAKDOWN OF CRISSES

3451 Crises in Total

570 ER Visits

165 Admissions to hospital
Key findings from Crisis Study

- Many people with DD will visit the emerg dept.
- Predictors of who goes:
  - No crisis plan
  - No primary care
  - Living with family
  - Mild disability
  - No forensic history
- Visits can be traumatic and reasons for hospital admission are complex
MOVING from Knowledge to Action

- HOW TO PACKAGE IT RIGHT?
- ASK YOUR FRIENDS FOR ADVICE!
- Real life quotes and stories
- Simple numbers
- Academic publications
What doesn’t work

- This lady said to me “you come in here all the time and this and that… She argued with me. I was upset about it so I just left and went to another hospital
- They don’t understand that it is hard to be cooperative when I am agitated
- Sometimes I get sent home from the ER even though I am suicidal. It is as if they are angry at me for trying to commit suicide. They don’t understand what a serious problem it is for me
- When I got handcuffed by police: It scared the heck out of me
- I had to wait a long time… Then I was with all these people with mental problems. Like one guy was kicking the door and a lot of people were making noises…It wasn’t a good experience
“When we see our kids treated this way and it's difficult not that I would do it but sometimes when you see people do some weird stuff with themselves and their kids, it takes situations like these when you reach out to people and they're looking at you as if you're piece of garbage or what you're saying doesn't matter. …You just put the person there or you give them some medication.

It takes more than that. You wouldn't like to see your family member going through that and no one is there to help. Show a little bit more kindness. Have a heart because the profession you're in you vowed to help people so that's what we expect from you. Help, that's what we want.”
If 1 in 2 people with dual diagnosis is going to the ED at least once in the next 2 years....
Correspondence

Are adults with developmental disabilities more likely to visit EDs? 

To the Editor,

This brief report presents the first North American population data on rates of emergency department (ED) use among adults with intellectual and developmental disabilities (IDD) relative to the general population. Individuals with IDD are at greater risk for health problems compared with the general population [1,2] and have higher morbidity and earlier mortality as a result. Illness in individuals with IDD can be further exacerbated in a health care system that is fragmented and inadequately resourced, particularly when medical professionals do not have the necessary expertise [3]. These issues are magnified when, in addition to chronic and acute medical concerns, a comorbid mental health issue emerges. Consequently, individuals with coexisting IDD and psychiatric disorder have been identified as a group with particularly complex service needs [4].

Perhaps one of the most problematic settings for individuals with IDD and psychiatric disorder is the hospital ED. In addition to their difficulties communicating their health issues and navigating the health system [1], they may need to contend with emergency staff who feel untrained and uncomfortable working with them [5,6]. Only 2 studies have examined patterns of ED use in samples of adults with IDD relative to the general population [7,8], but both have focused on medical (nonpsychiatric) emergencies. A third study on high ED users identified IDD as a predictor of frequent psychiatric visits [9]. Together, these studies demonstrate that, with or without psychiatric issues, individuals with IDD are at risk for ED visits.

The current study examines ED services used by the population of adult Ontarians with IDD, with and without psychiatric disorder, relative to Ontarians without IDD. Until now, this issue could not be studied because the presence of IDD was not systematically recorded in existing ED data. However, through linkage of several health data holdings (eg, physician billing data, hospitalization data) at the Institute for Clinical Evaluative Sciences in Ontario, Canada, we were able to create a service-based IDD cohort with and without psychiatric disorder, using a modified version of a previously described algorithm [10] to evaluate their ED patterns. In brief, persons were included in the IDD cohort if they had 1 of the following diagnoses: pervasive developmental disorders, mental retardation, fetal alcohol syndrome, and chromosomal and congenital anomalies for which an intellectual or developmental disability is typically present (eg, Down syndrome).

Emergency department visits for 2 years (fiscal years 2007/2008 and 2008/2009) were identified using the National Ambulatory Care Reporting System. Visit rates were compared for 2 IDD groups (those with and without a psychiatric disorder) as well as for 2 groups with no IDD (those with psychiatric disorder only and a random sample of the general population). We also examined ED triage level (ie, semiumergent and nonurgent vs emergent and urgent visits) [11] and after-hour vs regular-hour visits as indirect measures of the accessibility or adequacy of non-ED types of care. In addition, the percentage of “high users,” people with 5 or more visits in 2 years, was compared across the 4 groups.

Both IDD groups had consistently higher rates of ED visits when compared with the non-IDD groups (Table 1). The ratio of semiumergent and nonurgent to emergent and urgent triage level visits was greater for both IDD groups than for the non-IDD group. This finding is consistent with the notion that EDs have become a preferred setting for care for individuals with IDD and psychiatric disorder, in part because of the perceived difficulty of accessing other forms of care. The higher percentage of high users in both IDD groups suggests that ED visits are being used as a substitute for primary care and outpatient services.
Brief report

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

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Abstract

**Background** Stressful life events have been linked to psychopathology in the general population, but few studies have considered the relationship between life events and psychopathology for people with intellectual disabilities (ID), and the link between particular life events and hospital use.

**Methods** Informants provided data on 746 adults with ID who had experienced at least one ‘crisis’. Informants completed a checklist of recent life events from the Psychiatric Assessment for Adults with Developmental Disabilities Checklist (PAS ADD checklist) and also indicated whether the crisis resulted in a visit to the hospital emergency department.

**Results** Individuals experiencing life events in the past year were more likely to visit the emergency department in response to crisis than those who did not experience any life event. Individuals experiencing a more of hurt or violence, serious than 1 month, recent trauma/abuse, or a drug or alcohol problem were more likely to visit the emergency department.

**Conclusions** Six specific life events were found to be associated with use of emergency departments in response to crisis. We suggest intervention efforts be targeted towards people who experience life events, particularly these events, as they may be a risk factor for hospital visits.

**Keywords** emergency departments, hospitals, intellectual disabilities, life events

Introduction

The relationship between life events and psychopathology has been extensively studied in the general population (Dohrenwend & Egri 1981; Wills et al. 1992; Kendler et al. 1999). Less research has been conducted on the relationship between life events and psychopathology for individuals with intellectual disabilities.
Individuals With Intellectual Disabilities Who Live With Family and Experience Psychiatric Crisis: Who Uses the Emergency Department and Who Stays Home?

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Many individuals with intellectual disabilities who live with their families experience mental health problems and ensuing psychiatric emergencies. During periods of crisis, families may require additional services, including going to the emergency department (ED). The goal of this study was to elucidate demographic, clinical, and crisis features associated with ED use in 192 individuals who lived with family and experienced a psychiatric crisis. The presence of psychiatric symptoms, a mild (vs. moderate/severe) level of intellectual disability, a history of behavioral problems, psychiatric hospitalization, and ED use; and a recent history of negative life events were related to ED use. Learning about the factors that distinguish groups is needed to make sure we develop proactive community-based resources for such people to prevent visits to the ED from occurring when possible.
Moving from knowledge to action

SPRINKLE A LITTLE BIT OF WISDOM EVERYWHERE

- Primary care guidelines and tools
- Teaching of psychiatry residents
- Family guide
- CAMH website
- Mental health knowledge exchange network with link to Videoconference at OTN
## Essential Information for Emergency Department (ED)

**Name:**

**Address:**

**DOB:**

**Gender:**

**Tel:**

**Age:**

**Health Card #:**

### CLIENT INFORMATION:

- **Prefers to be called:**

- **Lives with:**
  - [ ] family
  - [ ] group home
  - [ ] supported independent living
  - [ ] other

### EMERGENCY CONTACT INFORMATION:

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<th>Relationship:</th>
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<td>Substitute Decision Maker [ ] Yes [ ] No</td>
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### HEALTH AND SOCIAL AGENCY CARE PROVIDERS:

- **Family Physician:**
  - **Tel. #:**

- **Psychiatrist:**
  - **Tel. #:**

- **Case Manager:**
  - **Name:**
  - **Agency:**
  - **Tel. #:**

- **Other agencies involved, contact person’s name**
  - [ ]
  - [ ]
  - [ ]
  - [ ]
  - [ ]

### REASON FOR REFERRAL TO ED:

- Safety risks to self, others or environment? [ ] No [ ] Yes (specify):

### BRIEF OVERVIEW OF HEALTH STATUS:

Include diagnoses, allergies, aetiology of developmental disability (DD) & level of functioning, health issues and risks – physical and behavioural or mental health.
Guidance about Emergencies for Caregivers

**ATTEND TO SAFETY ISSUES**

How can the person in crisis, staff, other residents and the environment be kept safe?

- Use existing successful strategies to manage escalating behaviours
- Can the person with developmental disability (DD) be safely contained in a quiet, safe place?
- What changes can be made in his/her environment to make him/her, other people, and the environment safe?
- Is there “as needed” or PRN medication that generally helps the person, and that can safely be given?
- Physical restraint is against policy, and not a legal option in group homes

**KEEP IN MIND**

- Person with DD and caregiver preferences in decision-making process
- Attend to uniqueness of the person with DD

**POINT OUT**

- Any possible medical symptoms that family/staff may have noticed, for Emergency Medical Services (EMS) and Emergency Department (ED) staff
- How the person typically communicates pain and distress

**IF SENDING THE PERSON WITH DD TO EMERGENCY DEPARTMENT OR CALLING 911:**

- Complete and send *Essential Information for Emergency Department (ED)*
- Attach list of all current medications from Medication Administration Record (MAR) or Pharmacy list and bring medications
- Consider bringing photos or video showing how this person acts when calm and not calm

**WHEN CONTACTING 911**

- Explain that the person has a developmental disability
- Alert EMS staff to any special needs, for example:
  - Best way to communicate
  - Importance of caregiver presence to help the person feel safe and comfortable
  - Sensitivity to sensory issues (e.g., noise, lights, textures, personal space)
  - Sensitivity to restraints
  - Reaction of the person with DD to uniformed police, and other people in uniforms or strangers

**IF PRN IS ALREADY PART OF THE BEHAVIOURAL MANAGEMENT PLAN:**

- Ensure that PRN medication is available and easily accessible
- Follow the administration and management according to the plan
- Monitor the person for potential side effects

**FOLLOW-UP:**

- Discuss the experience with the person and family to gather feedback and adjust the plan accordingly
- Evaluate the effectiveness of the strategies and make necessary adjustments

**REMEMBER:**

- Always prioritize the person’s safety and well-being
- Communicate effectively with all involved parties
- Arrange for ongoing support and follow-up care

**LEGAL CONSIDERATIONS:**

- Ensure that all actions are compliant with legal and ethical guidelines
- Consult with legal and medical professionals as needed

**CONTINUING LEARNING:**

- Stay informed about best practices and new developments in emergency care for people with developmental disabilities
- Participate in training and workshops focused on emergency management
Work with your friends...

- Remember what influenced those kids to wash their hands

What can we do to bring these findings into action? What other projects can we work on together?
I am feeling optimistic...

- Local discussions with ED staff and clinical service providers
  - Planning for one client successfully
  - Protocols that work for the community
- Crisis plans being adopted more broadly
- Families finding the information useful too