



# Improving emergency care for people with developmental disabilities

## What does the research tell us?

## Health Needs of Women with Mental Retardation and Developmental Disabilities

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The Women's Health Initiative (WHI), described by Matthews et al. (February 1997), is an excellent idea that it should be expanded to include research on underserved populations, especially women with mental retardation and developmental disabilities (MR/DD). The goal should be to study the health care needs of this population across the life span, not just in the postmenopausal phase of life. This report includes about 300,000 people in outpatient programs and an additional two million living independently or with their families.

Women with MR/DD are at greater risk for developing significant health problems than their non-MR/DD counterparts, as a result, they receive significantly less

significant fear of examination. This fear is common according to the doctors at our university who are experienced on this issue.

In conclusion, the health care needs of women with MR/DD require special study and cannot be assumed by extrapolation from a general population study such as WHI. We call on the National Institutes of Health to expand its efforts in women's health to underserved populations and to include specifically health studies of women with MR/DD.

### REFERENCE

Matthews, K. A., Shumaker, S. A., Bowen, D. J., Langer, R. D., Hunt, J. R., Kaplan, R. M., Klages, R. C., & Ritenbach, C. (1997). Women's Health Initiative: Why now? What is it? *What's new? American Psychologist, 52*, 101-116.

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## Service Utilization Patterns in Parents of Youth and Adults With Intellectual Disability Who Experienced Behavioral Crisis

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Family caregivers play an important role in supporting people with intellectual disability (ID) and mental health problems whose challenging behaviors across the life span. Research indicates that parents of people with ID may vary depending on the age of the child and the severity of mental health problems. Often, individuals with ID experience behavioral crisis, and the purpose of this study is to understand parents' service utilization patterns. Forty mothers of youth and adults with mild ID shared their experiences of crisis and commented on service needs and barriers to service access. Results from a survey of 200 parents of youth and adults with ID are reported, as well as on the barriers to service access using an adapted version of the Need for Help Questionnaire (Dowling, Baker, & Koc, 2007). All parents had high levels of service need. Although most parents noted that they received services, many found that service effectiveness was limited. A greater proportion of parents of youth rated the information and mental health care for their child as effects compared with parents of adults. Barriers to service access for parents of youth centered around perceptions of their child's problem behavior, whereas parents of adults focused on perceptions of the service system. Input from caregivers can help identify deficiencies in the system that lead them to crisis and help tailor services to meet their needs. Research is needed to further elucidate different ways of engaging parents of youth and of adults to help them promote

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Health Care Access Research  
and Developmental Disabilities



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## Emergency Psychiatric Services for Individuals with Intellectual Disabilities: Caregivers' Perspectives

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Accepted for publication 10 October 2008

Background: Stressors on the mental health system and inaccessible services for individuals with intellectual disabilities (ID) often prevent caregivers from bringing individuals with ID to the attention of the system when in psychiatric crisis. The purpose of this study was to understand the experience of caregivers and adults with ID at a mental health institution, according to caregivers' perspectives.

Method: Focus groups were conducted with one group of unpaid caregivers (i.e. family members) and two groups of paid caregivers (i.e. staff from community agencies) from Ontario, Canada.

Results: Caregivers identified a number of issues centering on a lack of services, on respect, on knowledge and

### Introduction

Mental health problems have been found to occur in approximately 40% of the community with intellectual disabilities (ID) who live in the adults (Cooper et al. 2007), and psychiatric crises are a major reason for visits to the emergency department (ED; Sullivan et al. 2000) and for

## Unreported experience of women with intellectual disabilities receiving emergency psychiatric services in Canada: a qualitative study

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Hospital emergency departments are not well equipped to meet the needs of individuals with intellectual disability. Experiences can be very traumatic, particularly if the crisis is because of behavioral or psychiatric problems. A focus group study was conducted in 2005 in Toronto, Ontario, Canada, with 10 women with intellectual disabilities who had visited the emergency department.

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Method: Focus groups were conducted with one group of unpaid caregivers (i.e. family members) and two groups of paid caregivers (i.e. staff from community agencies) from Ontario, Canada.

Results: Caregivers identified a number of issues centering on a lack of services, on respect, on knowledge and

on expertise. Diagnostic over-reliance on medication was noted, as were several equivalent terms. Consistent approaches from care providers to deficiencies in the system may lead them to use the ID who other options have been exhausted. A number of recommendations can be implemented to improve emergency psychiatric care of adults with ID in the ED.

Keywords: caregivers, emergency services, health care delivery, intellectual disability, mental health, psychiatric crisis

Most people with ID obtain care from paid or unpaid (i.e. family) caregivers in the community throughout their lives (Heller et al. 1999; Oliver et al. 2005). While caregivers are aided by specialized supports and daytime activities when people with ID are younger and still in school, many of these supports are lost during the transition to adult services as a result of lone waitress

### Reference

[1] Cheng HH, Yen PC. Killip classification and glucose level in patients with acute myocardial infarction. *Am J Emerg Med* 2010;28:853-6.

Are adults with developmental disabilities more likely to visit EDs?<sup>1,2</sup>

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 to some of the general population (Harrison & J Child Fam Stud (2012) 21:457-465  
DOI 10.1007/s10826-011-9499-3

### ORIGINAL PAPER

## The Experience of Crisis in Families of Individuals with Autism Spectrum Disorder across the Lifespan

Stacy E. White · Carly McMorris · Jonathan A. Weiss · Yona Lunsky

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well-established that parents of individuals with autism disorder (ASD) experience significant ongoing risk, and research findings indicate stressors can act as a precipitant to crisis. In the current study, the experience of crisis in individuals with ASD from early childhood through adulthood was explored. A review of the literature and a synthesis of research findings were used to identify key themes. We explored the crisis experience from the perspective of the parents and the context of crisis, behaviors, and consequences (outcomes and risks). Similarities and differences in the crisis experience among varying age groups are discussed, as well as implications for practice and future research.

Stacy E. White · Carly McMorris · Jonathan A. Weiss · Yona Lunsky

experience related to raising a child with a disorder (ASD) has received considerable attention (Bristol 1987; Brookman-Frazee et al. 2005). When compared to parents of typically developing children and children with other disorders of children with ASD often report higher

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experiencing a move of house or residence, serious problem with family, friend or caregiver, problems with police or other authority, unemployed for more

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However, through linkage of several health data sets (eg, physician billing data, hospitalization data, Institute for Clinical Evaluative Sciences in Ontario) we were able to create a service-based IDD cohort without psychiatric disorder, using a modified but previously described algorithm [10] to evaluate patterns. In brief, persons were included in the IDD cohort if they had 1 of the following diagnoses: pervasive developmental disorder, mental retardation, fetal alcohol syndrome, and congenital anomalies for intellectual or developmental disability is typical (eg, Down syndrome).

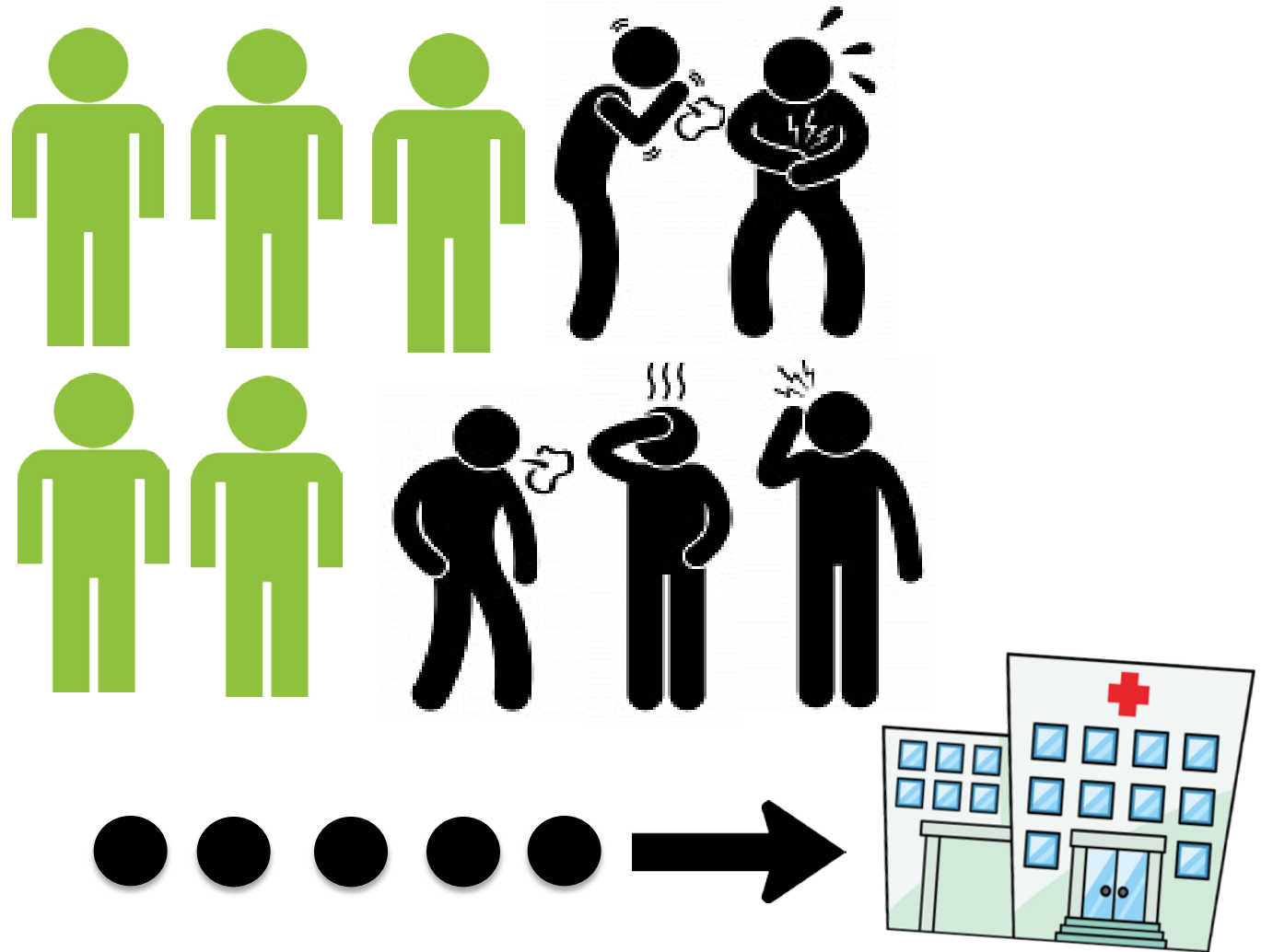
Emergency department visits for 2 years (from 2007/2008 and 2008/2009) were identified from the National Ambulatory Care Reporting System and were compared for 2 IDD groups (those with and without psychiatric disorder) as well as for 2 groups with

levels of stress and poorer family functioning (Dumas 1991; Konstantareas et al. 1992; Sanders and McConaughy 1997). This finding holds true for parents across geographic regions and cultures, with children at varying age and functioning levels (Koegel et al. 1992). Stress-coping models, such as the Double ABCX model (McCubbin and Patterson 1983; see Hassall et al. 2006 for review of models) have been used to understand the process of adaptation in parents of people with ASD. Crisis-related stressors (Bristol 1987). According to the Double ABCX model, poor parent outcomes, such as parenting stress (Duarte et al. 2005), marital problems (Renty and Roeyers 2007), or mental health problems (Stuart and McGrew 2009; Minnes et al. 2007) are a result of the severity of stressors and accumulated demands, the family's resources, the parent's perception of the situation, and their coping styles. Poor family adaptation can lead to situations of crisis when demands exceed parents' capabilities (Patterson 1987).

Research has found that challenging behaviors are perhaps the most pervasive and enduring source of stress among individuals with ASD over the lifespan (Hartman 2002; Tomaniuk et al. 2004). In a sample of 123 family toddlers with a pervasive developmental disorder, behavioral and emotional problems contributed significantly to maternal stress, parental psychopathology, and perceived family dysfunction (Herring et al. 2006). Consistent with these findings, Hastings (2003) and Lecavalier et al. (2006) found that challenging behaviors of school children and adolescents were significantly associated with maternal stress. Lecavalier et al. also reported that behavioral problems (specifically, non-compliance, conduct problem and maladaptive social behavior) were associated with stress in parents and teachers of children and adolescents with ASD. With regard to older individuals with

and psychopathology for individuals with intellectual disabilities (ID), despite studies that demonstrate that individuals with ID are more likely to have psychiatric disorders (Deb 2001) and that individuals with ID experience a greater number of life events than individuals without ID (Hartman & Emerson 2004). The existing research demonstrates

# 1 in 2 adults with a DD will go to the ED



# Epidemiology

## Ontario population study on ED and DD, Lunskey et. al

- Average # of visits among ED users = 3.0 vs 1.7
- 1.7 times more likely to be admitted
- ED visits can be VERY IMPACTFUL



# Epidemiology

## Ontario population study on ED and DD

- 25% of 18-24 y.o DD patients  $\geq$  2 meds
- 50%  $\geq$  2 meds by age 35



# Case Example

- 27 y.o. male w severe autism spectrum disorder. Non-verbal.
- Recent behaviour escalating to self-harm and harming caregivers after long stable period.
- ED referred to Psychiatry.
- Psychiatry referred to Medicine.
- Guess how long patient stayed in the ED?
- Guess what the final diagnosis was?

# DENTAL ABSCESS

- ....After **4 days** in the ED, and a range of PRNs to ‘manage his behaviour’ ....
- Dental pain is one of the commonly missed diagnoses among adults with DD (*see the clinical Tip Sheets*), and is well-established precipitant of behaviour change.
- We all missed it.



# Research Findings

## Predictors of emergency visits in DD

- No crisis plan
- Living with family
- Previous emerg visits
- Gaps in primary care



# What do we hear from patients and families?





- **Lack of respect**
  - Rights
  - Forced procedures
  - Treated for a different complaint
- **Consent**
  - Not given opportunity
- **Chemical and physical restraint**
  - Prior to alternative approaches

**“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 said they couldn’t keep her anymore  
so they sent her home...

The same day they sent her home,  
she ran away...

She has never taken the bus on her own but  
that day she took herself to another  
hospital.”



***“It was a bit difficult because the more people came in with other problems, the more anxious she got. Its not like a regular individual who could understand the wait.”***





**“They don’t understand that  
it is hard to be cooperative  
when I am agitated.”**

# What do we hear from Emergency Department staff?



**“How can I engage with this person?”**



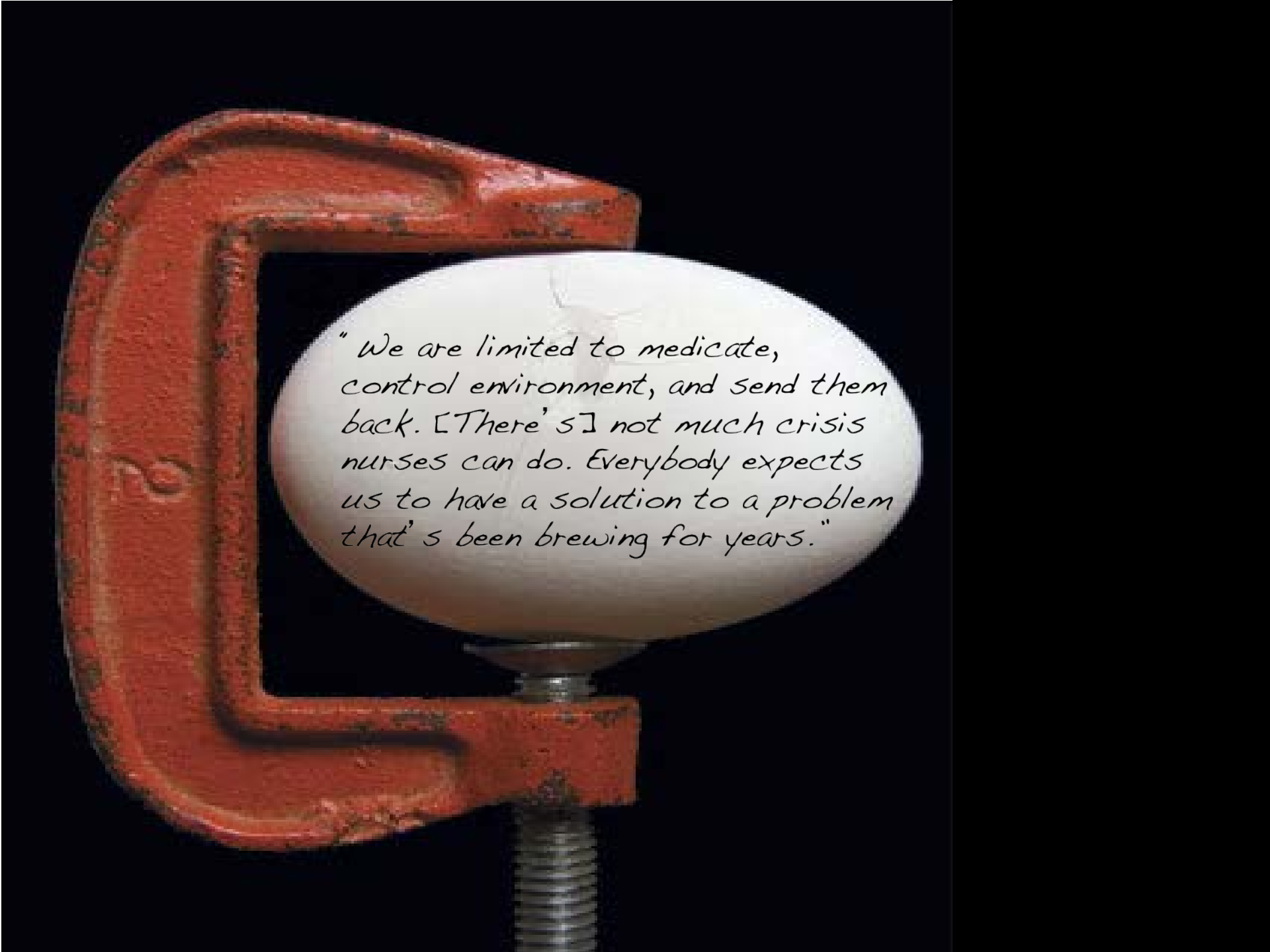
**...We don't have that expertise.”**





“We don’t see a lot, but when we do, they are time consuming and difficult...”

Sometimes the same person comes 3 to 4 times **in a row**".

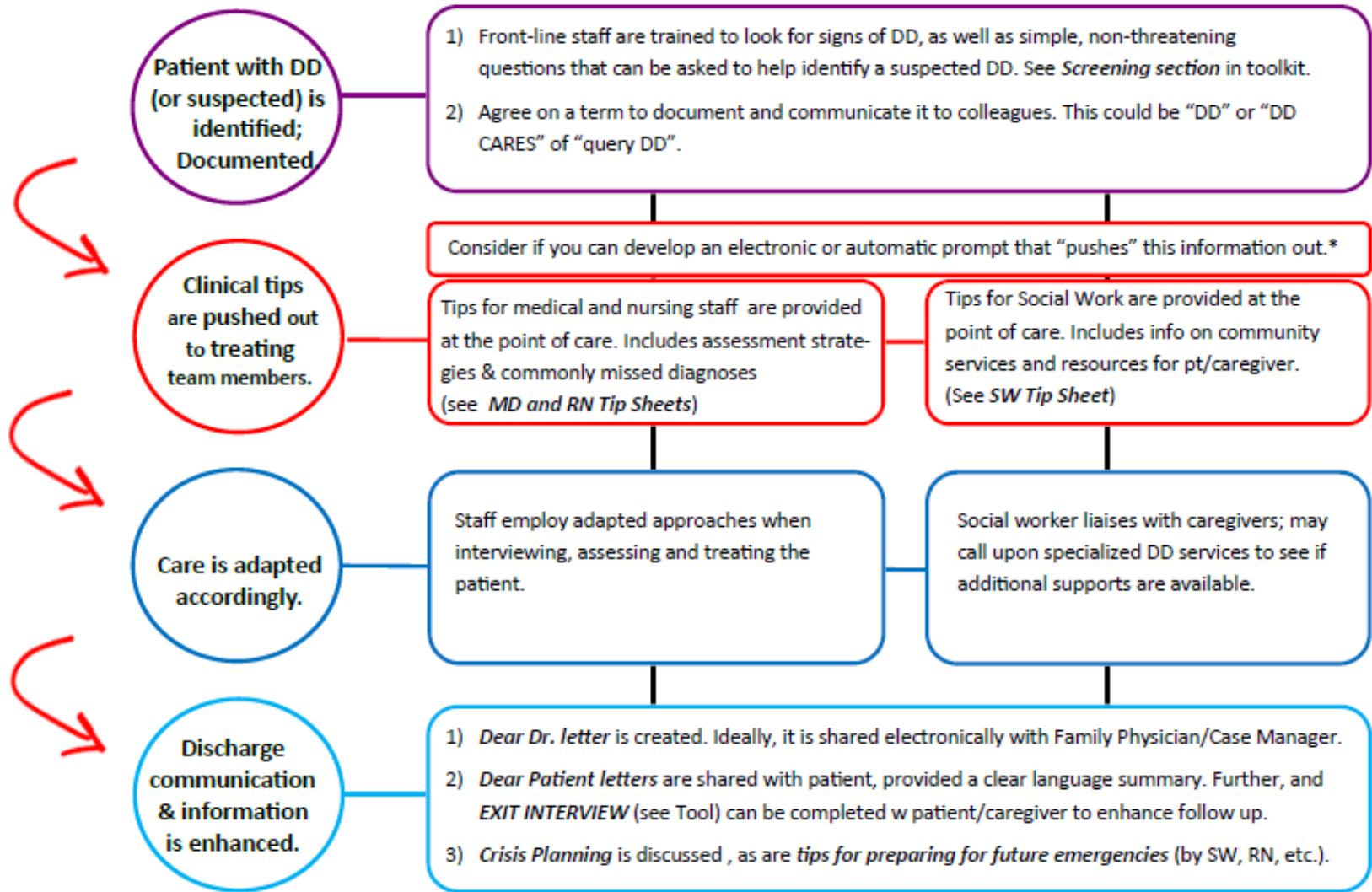
A photograph of a white egg with a visible crack, held in a red C-clamp. The background is solid black. The text is written in a cursive, handwritten style on the egg's surface.

*" We are limited to medicate,  
control environment, and send them  
back. [There' s] not much crisis  
nurses can do. Everybody expects  
us to have a solution to a problem  
that' s been brewing for years."*

**How are we going to help  
improve outcomes in our ED?**



# Example of the ED Intervention for patients with Developmental Disabilities



\*See *electronic infrastructure tip sheet* for ideas.

# How will we get there?

- **Enhance Communication**
  - With patients: Practical interview tips
  - With each other: Document DD in the chart
- **Fill Knowledge Gaps**
  - Medical issues specific to DD clients
  - Community resources for this population
- **Fit these resources into our ED Context**
  - Recognize time and shift-work realities in the ED
  - Embed into electronic or existing infrastructure.

# Identifying People with DD

*Goal:* Enhance Recognition to improve ED response

*Barrier:* Discomfort with “labelling”

*Facilitator:* Highlight benefits TO THE ED

# Adapting Approaches

*Goal:* Use of best evidence tools, strategies & techniques

*Barrier:* Integrating resources into ED best practices & procedures.

*Facilitator:* Understanding ED best practices and procedures and customizing accordingly (e.g. electronic prompts, visual aids, just-in-time).

# Recognize the ABC's

**A** All

**B** Behaviour is

**C** Communication



# Adapting Approaches

- We know how to do this... we just have to remember TO DO it
  - Slow down, sit down
  - Body language is important
  - Pick up on their verbal and non-verbal clues
  - See the clinical **TIP SHEETS**.
- 
- Laying down the law.... Not likely to help!

# Educational Videos

‘poor care’ scenario:

<https://vimeo.com/camheducation/review/73944562/2eec28eb53>

‘improved care’ scenario:

<https://vimeo.com/camheducation/review/73945180/97da0ee1aa>



# Discharge Planning

*Goal:* Improve information given to patients and providers & reduce future repeat visits

*Barrier:* **WORK FLOW, WORKFLOW, WORK FLOW !!!**

*Facilitator:* Ownership across the ED process & Minimizing additional work for staff

# Today's ER Visit: **My Exit Interview**

A summary of today's visit, to  
improve continuity of care.

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Hospital: \_\_\_\_\_

### For ED Staff:

- Review and discuss the visit and next steps in clear language with the patient.
- Ask them to rephrase or repeat to see they understand
- Fax this Exit Interview to their caregivers/community workers if at all possible.



Submitted by [D. Hefferon](#)

referral Form

2. Was the visit triggered by a behavioural issue (pick best response)

3. Was the visit triggered by/accompanied by mental health issues? (pick best response)

4. Collateral information was obtained from:

5. Was a DD CARES hospital passport/AboutMe document (or similar) used during this visit?  Yes  No  Don't Know

6. Did the patient come to the emergency department with a crisis or care plan?  Yes  No  Don't Know

7. Investigations  Yes  No

If Yes: CBC  electrolytes  Cardiac enzymes  Other bloodwork  Cultures

Any Abnormalities detected  Yes  No

#### Imaging

If Yes: X Ray  Ultrasound  CT Scan  MRI  EKG  Other

8. New medications:  Yes  No  
Type of medication  Name of Medication

9. Referrals made:  Yes  No

Patient Copy:

Dear JANE SMITH

You came to Sunnybrook hospital on 11/08/13 06:12:00 date because of ARRHYTHMIA, WOKE UP THIS AM AT 0530 HEARING A BEEPING SOUND FROM HER PACEMAKER, NO C.P., SLIGHT SOB, CHEST CLEAR, NO N&V, NO DIZZINESS, NO OTHER C.O., FREQ PVC.

While you were here, you saw D. Hefferon.

You received new Not applicable medication

We think that you have .

You have been referred to eye clinic

If there is someone who helps you (doctor, family member, staff person), please share this letter with them.

If you have any questions, please ask the doctor, social worker, or nurse who is helping you today.

If you have not been given an Exit Package, please ask someone in the emergency department for one before you leave.

If you do not have a care plan or crisis plan, please complete one before your next visit. You can find blank care plans at: [www.ddcares.ca](http://www.ddcares.ca)

The emergency department social worker may contact you in a few days to make sure you understood what happened in the emergency department today. The social...



# References

- Tint A, Lunsky Y. [Individual, social and contextual factors associated with psychiatric care outcomes among patients with intellectual disabilities in the emergency department.](#) J Intellect Disabil Res. 2015 Nov;59(11):999-1009.
- Lunsky Y, Paquette-Smith M, Weiss JA, Lee J. [Predictors of emergency service use in adolescents and adults with autism spectrum disorder living with family.](#) J Emerg Med J. 2015 Oct;32(10):787-92.
- Lunsky Y, Lin E, Balogh R, Klein-Geltink J, Wilton AS, Kurdyak P. [Emergency department visits and use of outpatient physician services by adults with developmental disability and psychiatric disorder.](#) Can J Psychiatry. 2012 Oct;57(10):601-7.
- Lunsky Y, Balogh R, Khodaverdian A, Elliott D, Jaskulski C, Morris S. [A comparison of medical and psychobehavioral emergency department visits made by adults with intellectual disabilities.](#) Emerg Med Int. 2012 :427407.
- Lunsky Y, Balogh R, Cairney J. [Predictors of emergency department visits by persons with intellectual disability experiencing a psychiatric crisis.](#) Psychiatr Serv. 2012 Mar;63(3):287-90.
- Lunsky Y, Elserafi J. [Antipsychotic medication prescription patterns in adults with developmental disabilities who have experienced psychiatric crisis.](#) Res Dev Disabil. 2012 Jan-Feb;33(1):32-8.
- Sullivan WF, Berg JM, Brrdley E, Cheetham T, Denton R, Heng J, Hennen B, Joyce D, Kelly M, Korossy M, Lunsky Y, McMillan S; [Primary care of adults with developmental disabilities: Canadian consensus guidelines.](#) Colloquium on Guidelines for the Primary Health Care of Adults with Developmental Disabilities. Can Fam Physician. 2011 May;57(5):541-53.
- Lunsky Y, Elserafi J. [Life events and emergency department visits in response to crisis in individuals with intellectual disabilities.](#) J Intellect Disabil Res. 2011 Jul;55(7):714-8.
- Lunsky Y, Lin E, Balogh R, Klein-Geltink J, Bennie J, Wilton AS, Kurdyak P. [Are adults with developmental disabilities more likely to visit EDs?](#) Am J Emerg Med. 2011 May;29(4):463-5.
- Lunsky Y, Gracey C. [The reported experience of four women with intellectual disabilities receiving emergency psychiatric services in Canada: a qualitative study.](#) J Intellect Disabil. 2009 Jun;13(2):87-98.
- Lunsky Y, Gracey C, Gelfand S. [Emergency psychiatric services for individuals with intellectual disabilities: perspectives of hospital staff.](#) Intellect Dev Disabil. 2008 Dec;46(6):446-55.