Finding your way through the healthcare maze: Lessons from research on health services and ASD

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Autism ONTARIO
see the potential voir le potentiel



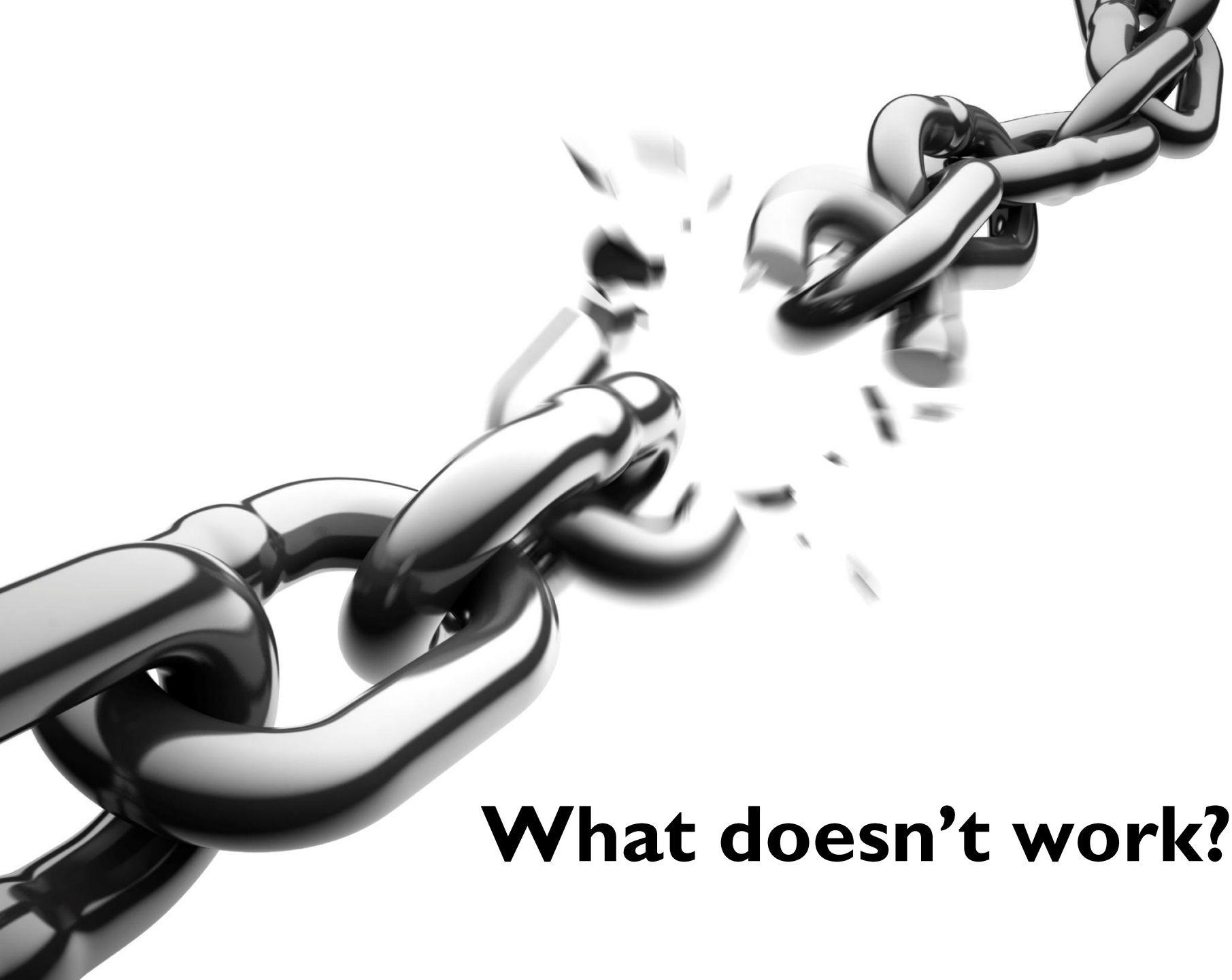
CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada



Ontario
MINISTRY OF HEALTH AND LONG-TERM CARE


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[plural] 1 serious st
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What we can learn from people who have been there?



What doesn't work?



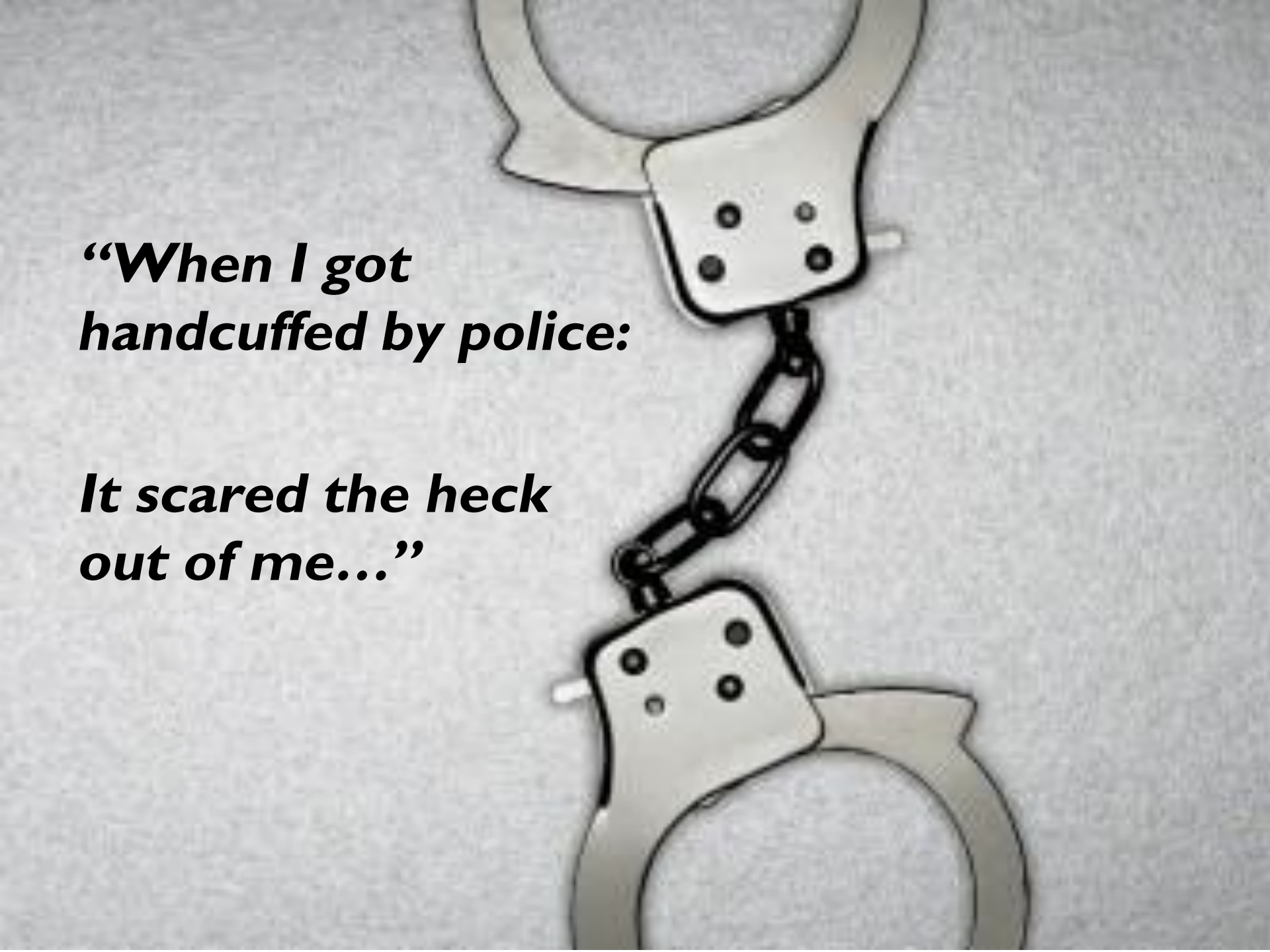
"This lady said to me 'you come in here all the time and this and that…' She argued with me. I was upset about it so I just left and went to another hospital."



"They don't understand that it is hard to be cooperative when I am agitated."



"This is the third time my son has been to the emergency with suicidal ideations. Each time he is sent home. Does he have to attempt suicide before anyone takes notice?"

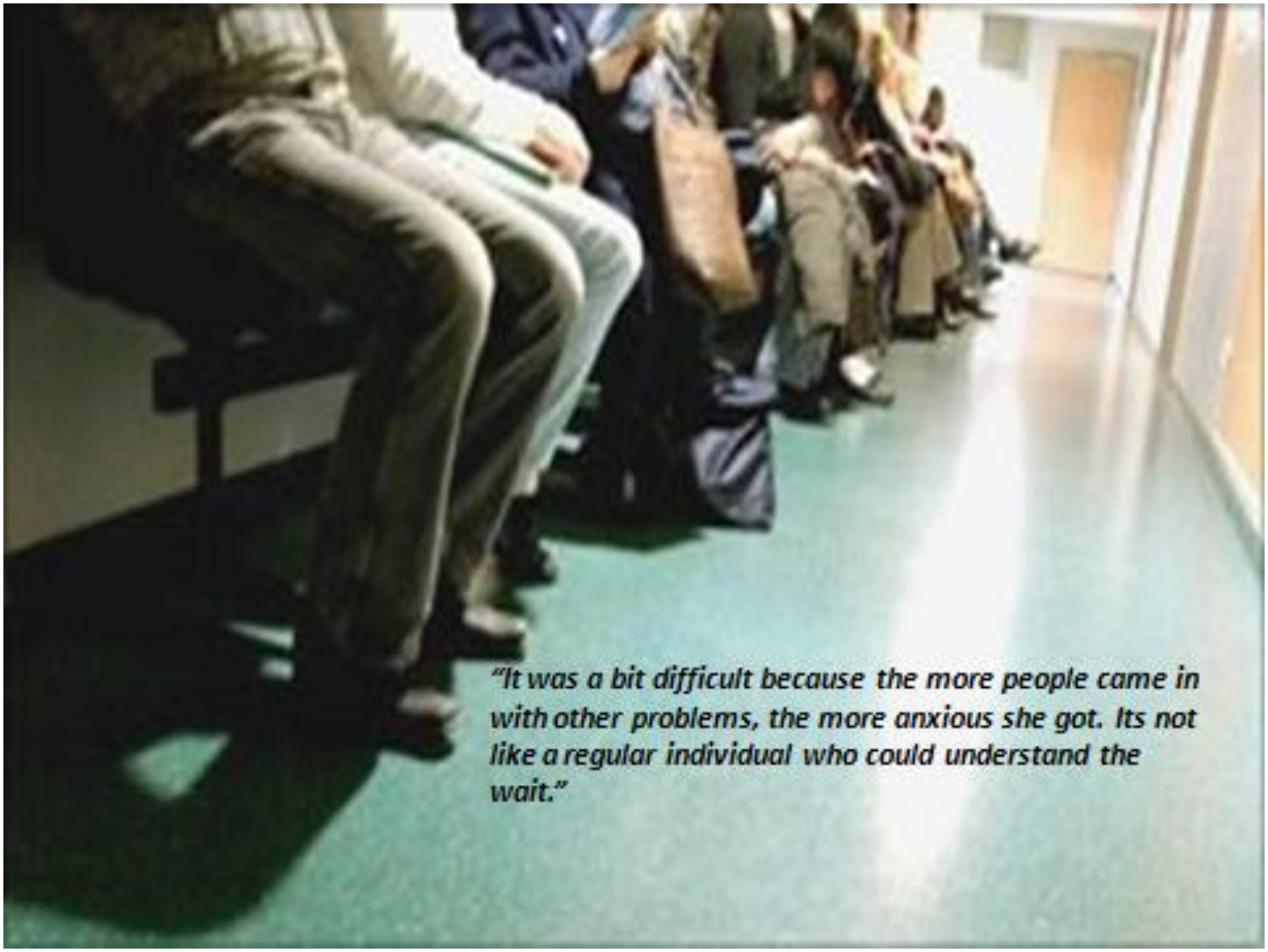

"When I got handcuffed by police:
It scared the heck out of me…"



"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."

Time in the emergency department




"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."



"We got there at 6 and got through around midnight. Then we waited until 7 in the morning to see the psych doctor."

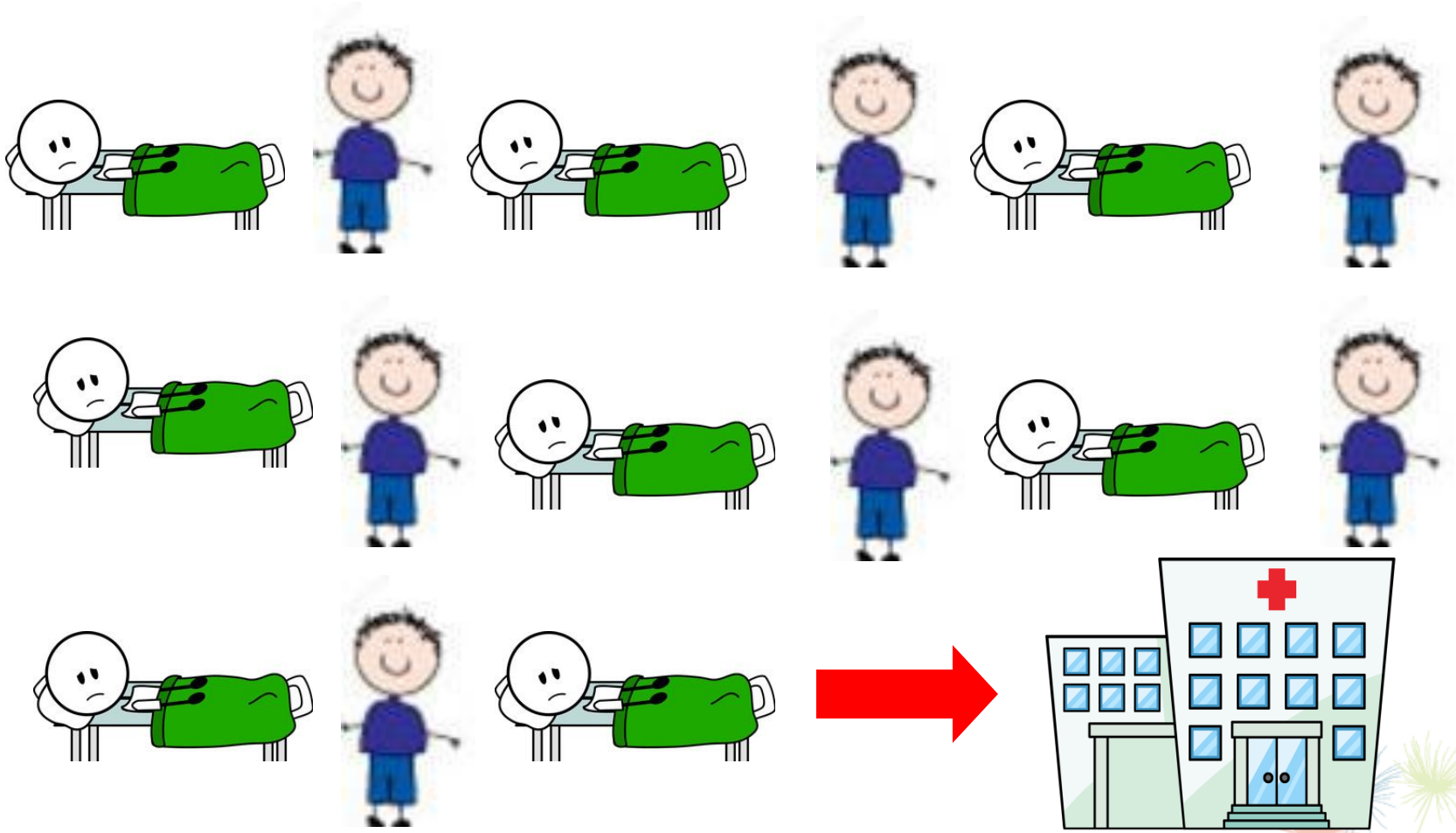


"They said they couldn't keep her anymore so they sent her home.

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."

In a 2 year period…



1 in 2 people with a DD will go to the ED.

Lunsky et al., 2011 American Journal of Emergency Medicine

Emergency service use



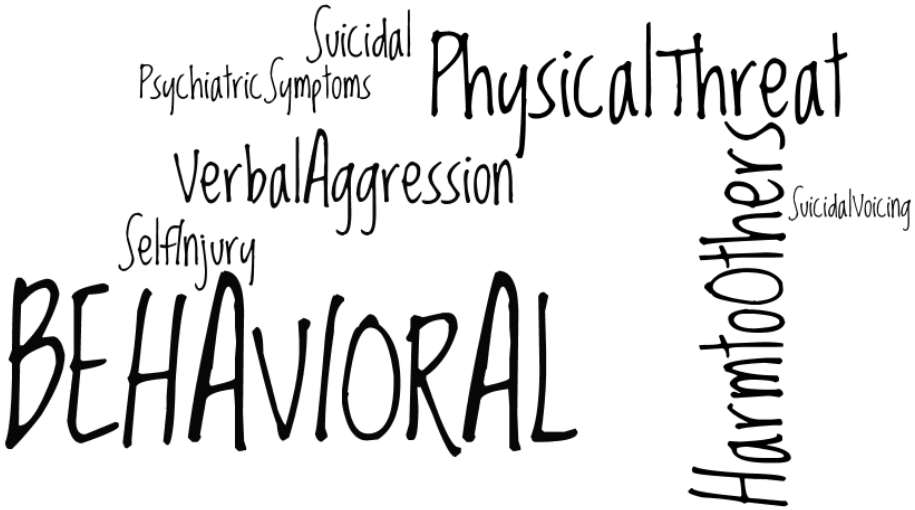
- 1 in 7 used emergency services over 2 months
- 1 in 4 used emergency services over 8 months

Risk factors for emergencies



- ED visits in last year
- History of hurting others
- No structured daytime activities
- Family in Crisis

Behavioural emergencies



Emergencies in which behaviour is <u>unusual</u>, <u>bizarre</u>, <u>threatening</u>, or <u>dangerous</u> that it is of concern to the patient or family

Lunsky, Khodaverdian et al., 2012

Medical emergencies



Emergencies that result from physical injury or illness

Lunsky, Khodaverdian et al., 2012



But there are many instances where behavioral and medical emergencies overlap

What predicts hospitalization?



What happened in the hospital…



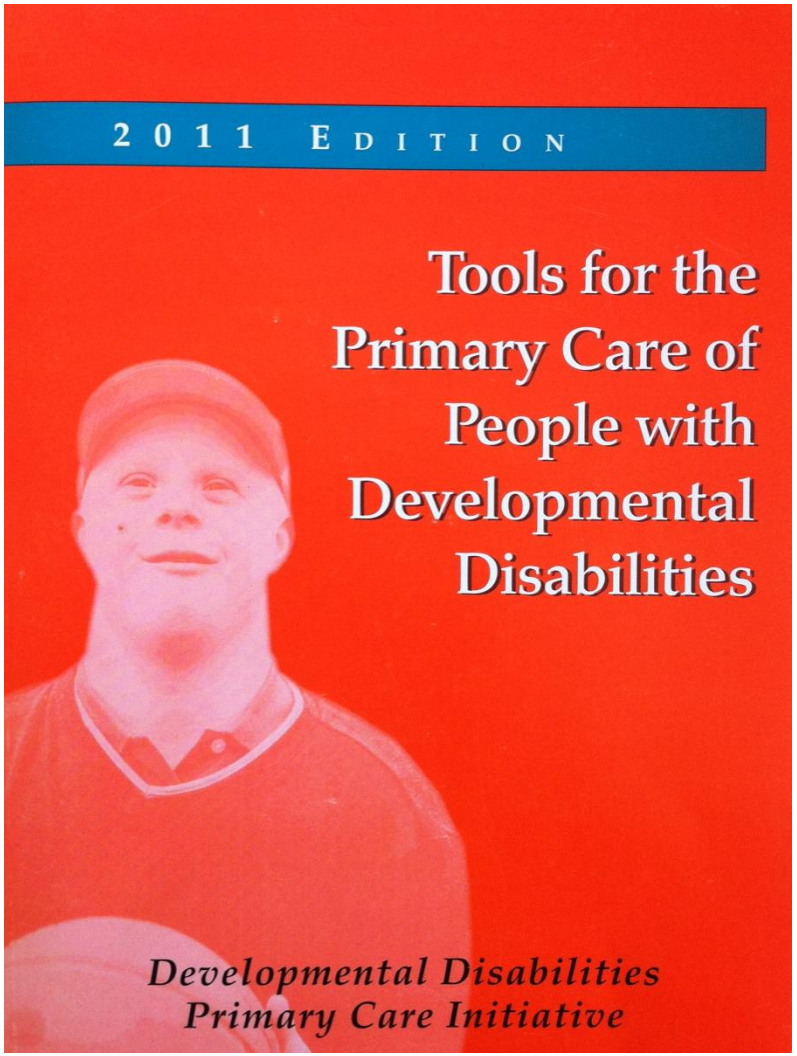
- Developmental disability was not recorded in the chart
- Caregivers often not included or mentioned in the assessment
- Many individuals were sent home before being assessed by psychiatry/crisis team
- Caregivers were less satisfied with psychiatric visits than medical ones

If 1 in 2 people with developmental disabilities is going to the ER at least once in 2 years…

We've got a problem on our hands.



How can we fix it?



Good primary care

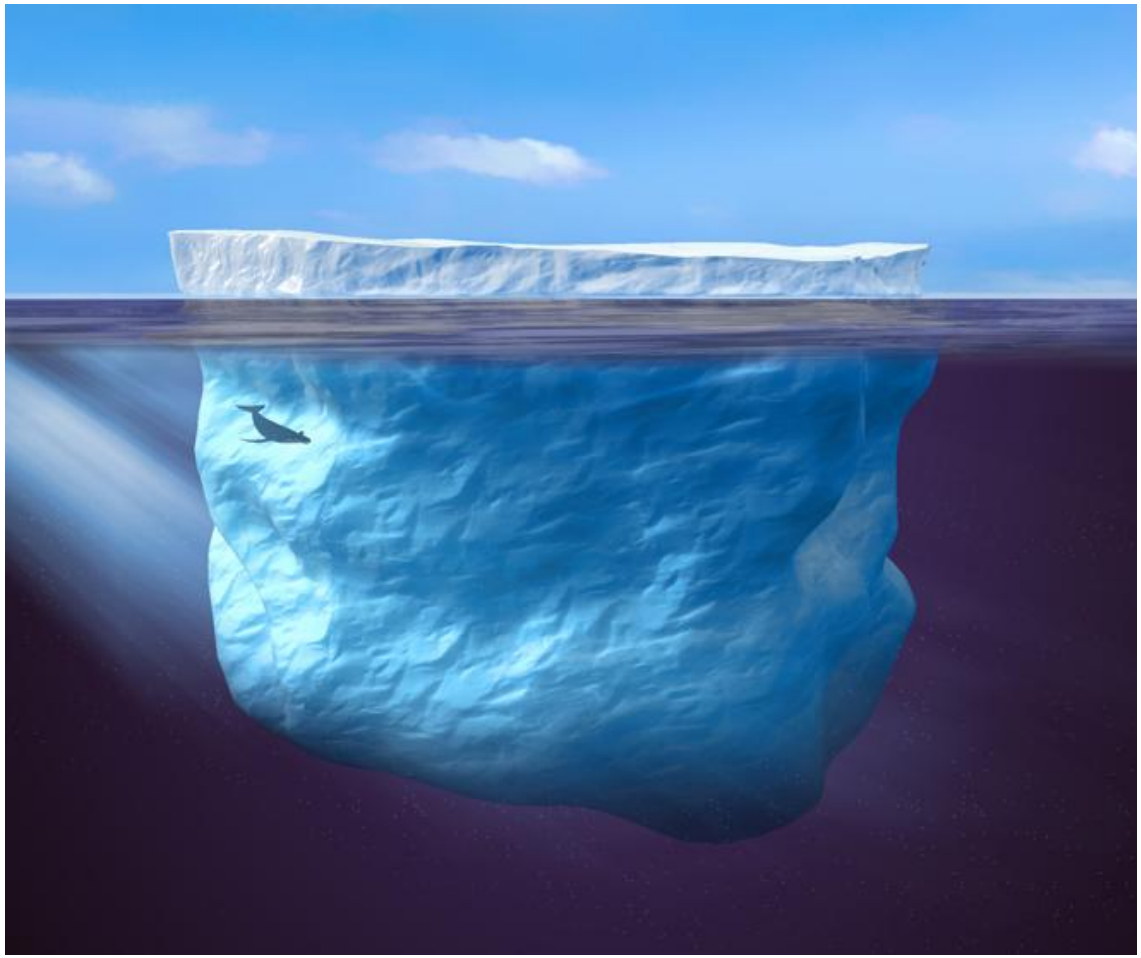
(recognize medical issues)



Medications



Life events





Offer alternatives to the unsupported.



Meaningful daytime activities & pleasant home environments.

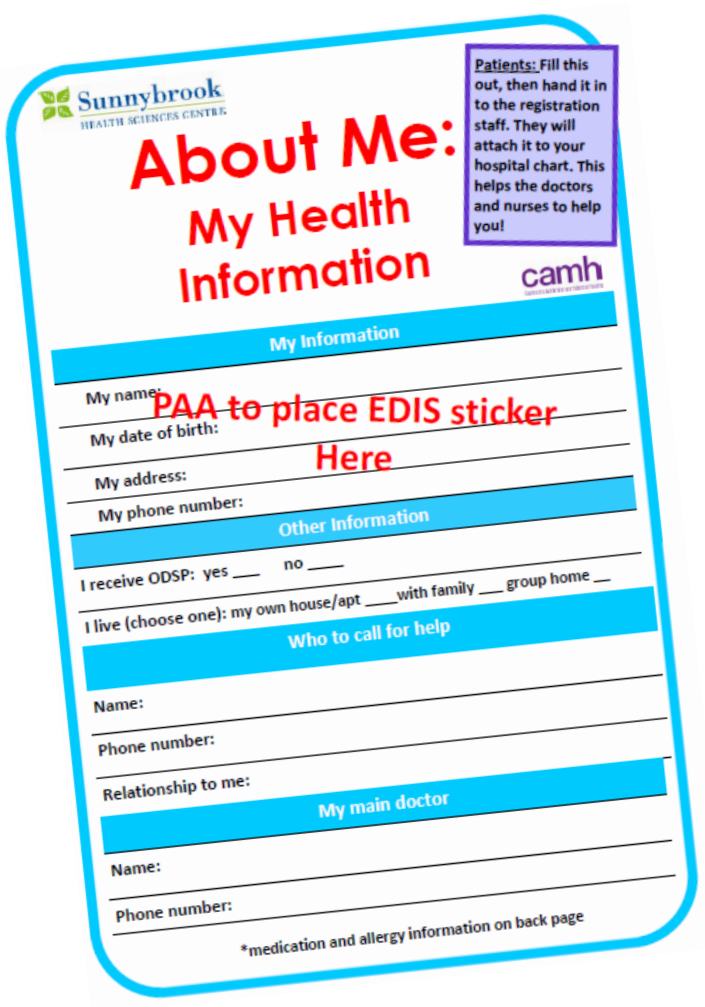
Are we learning each time?

The first visit to hospital might be an emergency but repeated visits represent our failure as a system to plan and put what is needed in place.

If 1 in 2 people with developmental disabilities is going to the ER at least once in 2 years…

THEN LET'S PREPARE FOR IT.

Information for the hospital









Extensive crisis plans

Crisis Prevention and Management Plan [3]

for Adults with Developmental Disabilities (DD) at Risk of or During Behavioural Crises

A Crisis Prevention and Management Plan for an adult patient with DD addresses serious behaviour problems and helps prevent, or prepare for, a crisis. It describes how to recognize the patient with DD's pattern of escalating behaviours. It identifies responses that are usually effective for this patient to prevent (if possible) a behavioural crisis, or to manage it when it occurs. The Crisis Prevention and Management Plan is best developed by an interdisciplinary team.

- Describe stage-specific signs of behaviour escalation and recommended responses.
- Identify when to use "as needed" (PRN) medication.
- Identify under what circumstances the patient with DD should go to the Emergency Department (ED).

Crisis Plan for: _____ **DOB:** _____ **Date** _____

Problem behaviour: _____

Stage of Patient Behaviour	Recommended Caregiver Responses
Normal, calm behaviour	**Use positive approaches, encourage usual routines**
Stage A: Prevention (Identify early warning signs that signal increasing stress or anxiety.)	**Be supportive, modify environment to meet needs** (Identify de-escalation strategies that are helpful for this patient with DD).
Stage B: Escalation (Identify signs of the patient with DD escalating to a possible behavioural crisis.)	**Be directive** (use verbal direction and modelling), **continue to modify environment to meet needs, ensure safety**
Stage C: Crisis (Risk of harm to self, others, or environment, or seriously disruptive behaviour, e.g., acting out.)	**Use safety and crisis response strategies**
Stage R: Post-crisis resolution and calming	**Re-establish routines and re-establish rapport**

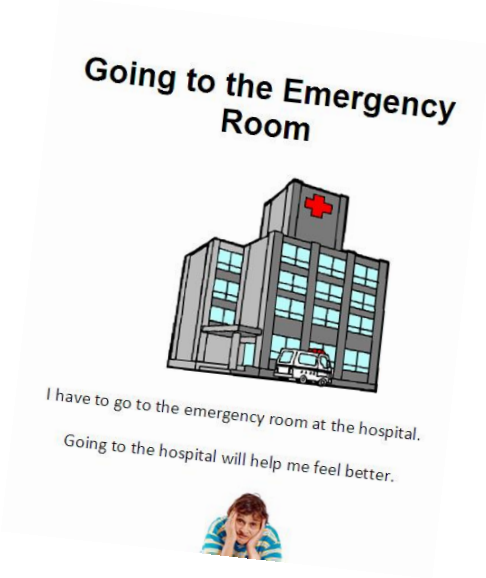

Emergency
packs in the
front hall
cupboard

Preparing for next time



Training on HOW to prepare

- DVD
- Social story
- Tour of hospital
- Emergency visit guide
- www.ddcares.ca (coming soon!)




Meanwhile, over at the hospital…

- Where do the forms go?
- How do they get the information they need?
- Focus is often just on today's issue



ED Developmental Disabilities Contact Sheet

	GATEWAY TO ADULT SERVICES	CRISIS & TRANSITIONAL SERVICES / RESPITE SUPPORTS	DUAL DIAGNOSIS
Agencies	**Developmental Services Ontario (DSO-TR)**	**Griffin (Crisis & Transitional)** **Respiteservices.com**	**CAMH: Dual Diagnosis Service**
Contact Info	www.dsotoronto.ca 1-855-DS-ADULT or (1-855-372-3858) dsotr@surreplace.on.ca	http://www.griffin-centre.org/ contact@griffin-centre.org 416-222-3563 (M-F, 9-4pm; Griffin) After hours contact: 416-929-5200 www.respiteservices.com info@respiteservices.com 416-322-6317 x1 (intake & info; 9-5)	http://www.camh.ca/en/hospital/care_program_and_services/dual_diagnosis_programs 416-535-8501 ext. 77809 (Toronto) 416-535-8501 ext. 37713 (Peel)
Hours	- 9-5pm (A navigator will return call within 24 hours)	**Griffin:** M-F, 9-6pm (intake will return messages within same day) After hours contact: 416-929-5200 **Respiteservices.com:** M-F, 9-5pm	- M-F, 9-5pm - phone calls will be returned within 1 business day
Service Criteria (age, diagnosis)	- 16+ years (services at 18) - Developmental disability (significant limitations in cognitive and adaptive functioning) or no diagnosis, but seeking an assessment	**Griffin:** 16+ years - Developmental disability or dual diagnosis (developmental disability + mental health issues). Documentation of diagnosis is generally not required **Respite:** Lifespan service. Families must be registered, children & adults with DD living in family home. If 18+ years confirmed eligible by DSO required	- 16+ years - Dual diagnosis (developmental disability: IQ 70 or lower & mental health needs) and/or · History of unclear assessment & diagnosis · Complex medical & mental health · History of ED use
Geographic Criteria	Toronto, Scarborough, North York, Etobicoke	**Griffin:** Toronto **Respiteservices.com:** Toronto	Toronto, Peel Region
Services Offered	• Information about available supports and services (both funded and non-funded) • Confirmation of eligibility to receive Ministry funded adult developmental services and supports, • Assistance completing Application Package to assess individual service and support needs • Creation of support plan Connection with available supports and services including specialized clinical services like behaviour therapy, psychiatry, occupational therapy, psychology	**Griffin:** (Crisis & Transitional): • Time limited supports including: • short term safe beds or day programs, • staffing supports, • interim case management, • crisis planning and consultation, access to specialized assessments through community partners consultation **Respiteservices.com** • Central resource for caregivers & professionals wishing to access respite supports & services in City of Toronto. • Contact online or by phone	• Consultation, assessment, diagnosis, • Time limited, community-based intervention/treatment • Medication review • Crisis planning • Through partnerships can offer education, training & system facilitation including assisting in making links to referrals for housing, vocational, educational and treatment services **Inpatient admissions to CAMH Dual Diagnosis Service are planned through outpatient services.**
Wait Times	DSO can connect you to services and determine eligibility, but there may be wait times (e.g., psychological assessment for diagnostic purposes may be 3 mos). DSO does prioritize based on the urgency of the case.	**Griffin:** if patient is in ED, will endeavor to send someone out to assess and consult, but this can take up to 72 hours. **Respiteservices.com:** Respite is a short, *planned* break. Not an emergency or crisis response service.	If acute crisis in ED, will respond by telephone within 24 hours. Can send Assessment Coordinator and RN within 2 business days for consultation if necessary.
Service Limitations	**Cannot** provide crisis response, but can refer to crisis services.	**Cannot** provide medical or mental health emergency services that require an immediate mobile crisis response.	**Cannot** provide crisis response, can offer assistance or direction over phone during business hours.

Updated April 15, 2013

Anyone can make a referral!

Essential Information for Emergency Department (ED)

Name: Gender:

Address: DOB:

Tel: Age:

Health Card #:

CLIENT INFORMATION: **Prefers to be called:**	**Lives with:** □ family □ group home □ supported independent living □ other
EMERGENCY CONTACT INFORMATION:	
Name:	**Relationship:**
Tel #: Home: Work or cell:	***Substitute Decision Maker*** □ ***Yes*** □ ***No***
Name:	**Relationship:**
Tel #: Home: Work or cell:	***Substitute Decision Maker*** □ ***Yes*** □ ***No***
HEALTH AND SOCIAL AGENCY CARE PROVIDERS:	**Preferred hospital/treatment centre:**
Family Physician:	**Tel. #:**
Psychiatrist:	**Tel. #:**
Case Manager: **Name:**	**Agency:** **Tel. #:**
Other agencies involved, contact person's name • • •	**Tel. #:**

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

Realistic expectations of the emergency department



- ✓ You will have to wait
- ✓ You will be asked the same questions more than once by different medical staff
- ✓ You need to make the link between your hospital consultation and your community care (PLAN DEBRIEF)

Realistic expectations of the emergency department

- ✓ Can help rule out medical concerns
- ✓ Can provide a safe place
- ✓ Can sometimes help to link with follow-up services
- ✓ Crisis planning/Exit Strategy



Realistic expectations of the emergency department

- May not be able to provide specialized assessment
- Can't provide a comfortable, quiet environment
- Can't provide ongoing therapy for client
- Can't fix the system



Resources

- http://knowledgex.camh.net/amhspecialists/specialized_treatment/dual_diagnosis/Pages/default.aspx
- http://www.cbc.ca/thecurrent/episode/2012/09/20/dual-diagnosis-the-long-way-home/
- www.hcardd.ca

ddcares@camh.ca