

**ADVOCATING FOR  
INSTITUTIONALIZED PEOPLE  
DURING COVID:  
THE MASSACHUSETTS EXPERIENCE**

**NARPA 2021**

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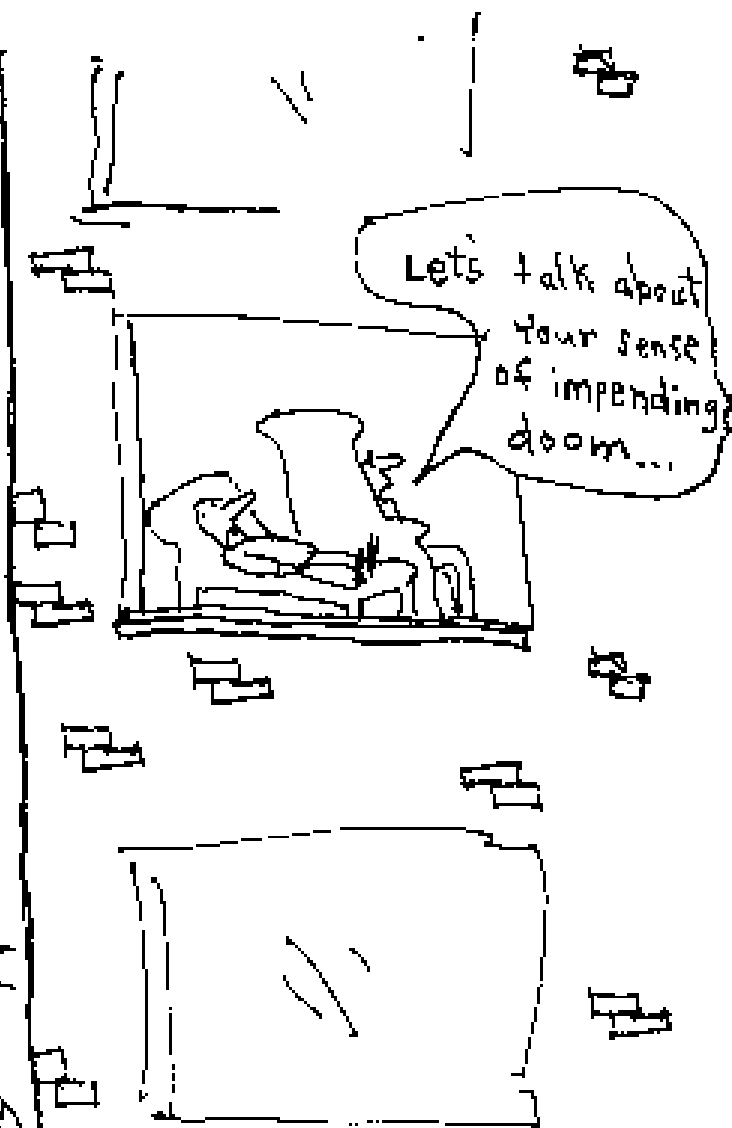


# Disability Rights Infrastructure

Existing disability rights organizations who rapidly and cooperatively work with each other and who

- Recognize Emerging Disability Rights Issues in Emergencies
- Are Proactive, not Reactive
- Act Immediately





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# FOUR EMERGENCY ISSUES IN PANDEMIC

1. People in Congregate Facilities, Jails and Prisons at Greatly Elevated Risk of COVID
2. Consequences of Lockdown
3. Overstrained Hospitals and ICUs Were Developing Triage Standards for Rationing Care
4. Hospitals Were Denying Visitation/Accompaniment



# Massachusetts Organizations

**CPCS:** public defender/MHLD

**DLC:** Mass. Protection & Advocacy

**MHLAC:** state MH rights agency

**CPR:** systemic advocacy people with psych/intellectual disabilities & brain injuries

**RLCs:** Grassroots peer support/advocacy organizations



# People in Congregate Facilities at Greatly Elevated Risk of COVID

1. CPCS:
  - a. Discharge non-violent, at-risk people
  - b. Add new element to commitment
2. DLC: investigated Tewksbury State  
Recommendations to better protect patients
3. MHLAC
  - a. Brought litigation against DMH over state hospitals with high infection and death rates



# People in Congregate Facilities at Greatly Elevated Risk of COVID

## 4. RLCs:

Provided Reliable Information to Members About COVID

Provided Alternative Services

Provided Advocates with Reliable Information about Hospital Conditions and Sources of Vaccine Hesitancy

Protest over Hospital Conditions at the Shattuck





# **TRIAGE ISSUES:**

## **EXPLICIT DISABILITY-BASED DISCRIMINATION IN EMERGENCY PLANS**

**Alabama:** Guidance for ventilator triage in emergency situations precludes ventilators for people with severe or profound retardation, moderate or severe dementia, and severe traumatic brain injury, including children.

**Tennessee:** excluding people with spinal muscular atrophy who need assistance with ADLs from critical care





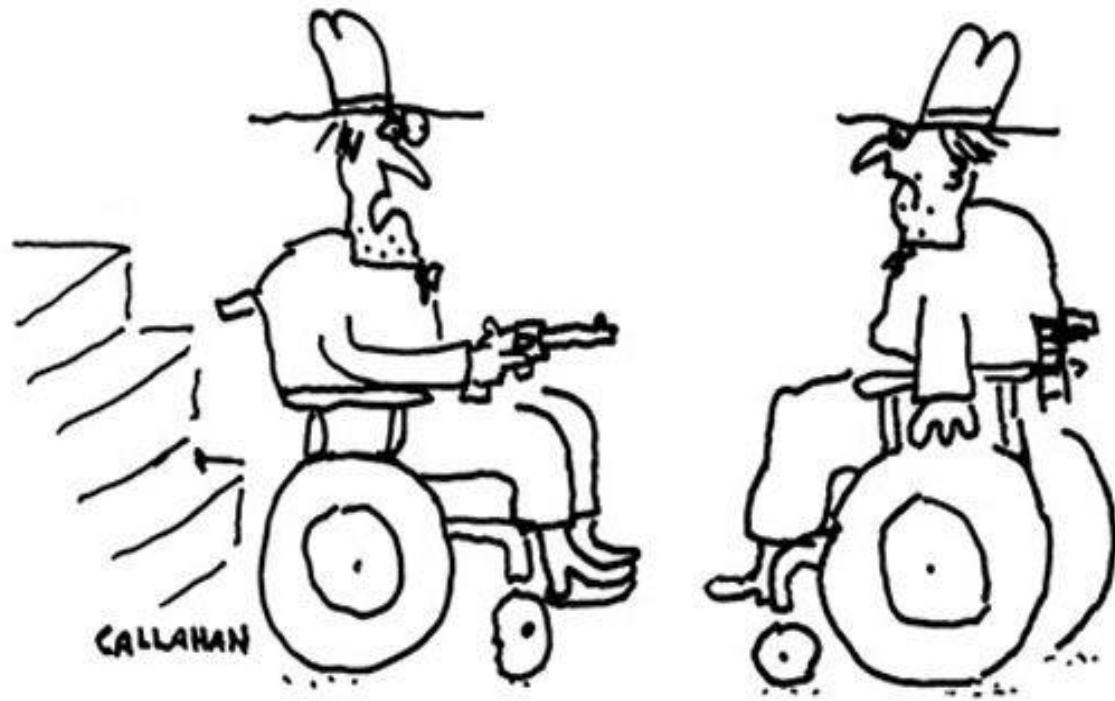
# **TRIAGE ISSUES**

**New York:** People with disabilities who used ventilators because of chronic disabilities faced possible loss of those ventilators

**Massachusetts:** Guidelines changed from long-term survival to short-term survival

**Washington:** Guidance to transfer people with “loss of reserves in energy, physical ability, cognition and general health” to outpatient or palliative care.





"THIS TOWN AIN'T ACCESSIBLE ENOUGH FOR BOTH OF US!"



# Timeline

March 10: Governor Baker declares pandemic emergency

March 12: Visitation restricted at nursing homes

March 19: Visitors restricted from state psych and other health care facilities

March 21: first COVID-positive prisoner

March 23: CPR files Triage complaint (Wash.)

March 24: CPR files Triage complaint (Ala.)

March 25: CPCS v. Chief Judge filed



# Timeline

March 26: CPR DLC MHLAC letter to Baker suggesting triage guidelines to prevent disability discrimination

March 27: CPR files complaint re Kansas Toolkit for COVID-19

March 28: HHS OCR Triage policy issued

March 31: Oral argument CPCS v. Chief Judge

April 3: SJC orders non-violent pretrial detainees entitled to rebuttable presumption of release >

# Timeline

April 16: Joint letter from DLC and MHLAC about conditions at Shattuck Hospital

April 16: 67 pts and 46 staff test positive at Tewksbury Hospital

April 21: first psych pt dies of COVID at Shattuck Hospital

April 23: DLC initiates investigation of COVID at Tewksbury

May 7: Foster complaint filed

May 7: SAMHSA Consideration for Care & Tx of Substance Abuse & Mental Disorders in the COVID-19 Epidemic 



# Timeline

May 7: SAMHSA Consideration for Care & Tx of Substance Abuse & Mental Disorders in the COVID-19 Epidemic

May 17: MASSAct protests at Shattuck Hospital

June 2: Foster decision adding extra elements to civil commitments

July 31, 2020: MHLAC sues Mass. DMH over Tewksbury conditions



# **Other States Were Doing This Too...**

**Alabama:** P&A complained about discriminatory triage standards

**California:** P&A sues Patton State Hospital, August 2020

**Connecticut:** CLRP on April 20 writes Conn. Gov. asking for ban on psych hospital admissions/expedited d/c

**Michigan:** Chief Justice tells judges to release more people on their own recognizance and use more probation and tx programs as alternatives





# **Other States Were Doing This Too...**

**New Jersey:** Office of Public Defender secures consent decree that suspends or commutes low-risk inmates

**South Carolina:** All non-capital defendants shall be released on recognizance without surety unless unreasonable danger to community or extreme flight risk.



# **Foster v. Commissioner of Dept. Corrections (*Foster 1*)**

1. About prisoners/people committed for substance abuse (Sec. 35), but language made clear it was applicable to m.h. commitments.
2. COVID affects whether commitment is narrowly tailored to meet gov't interests in safety and treatment.
3. Therefore, for the duration of the pandemic, the Supreme Judicial Court adds an element to the criteria for commitment:



# **Foster v. Commissioner of Dept. Of Corrections (*Foster 1*)**

3(a) No commitment unless the danger posed by the individual's substance use disorder outweighs the risk of transmission of COVID-19 in congregate settings.

3(b) Additionally, commitment must be necessary notwithstanding the treatment limitations imposed by quarantine protocols.



# IMPLEMENTATION OF THESE VICTORIES IN MASSACHUSETTS...

- 1. SJC ORDER TO DISCHARGE NON-DANGEROUS PEOPLE** met with resistance by District Court Judges and DAs.
- 2. TRIAGE VICTORIES LESS MEANINGFUL** if people with disabilities were unaccompanied or as applied to scarce resources such as ECMOs that were limited for non-disabled people as well



# LESSONS LEARNED FOR THE NEXT TIME...

## **1. Get your disability rights infrastructure in place, and working together**

### **SPECIFICALLY:**

a. civil commitments should be defended by an entity staffed by people who focus on this: Mass. model, NY model, Miami FI model, D.C. model, Minn. model

b. P&As should work regularly with ACLU, Legal Services, Public Defenders, etc.



# Lessons learned for the next time (cont.)

2. Make sure you know your state's triage Guidelines and fix discriminatory provisions before the next pandemic
3. District Attorney is an office that disability Rights advocates should pay more attention to, both in terms of education and election support --same with lowest level judges





# What needs to be done right now

Many civil rights were “relaxed” in light of the pandemic and society is only too willing to continue these practices:

- \*Zoom Commitment Hearings
- \*In-home Therapy for Disabled Kids

**Goal:** a world where decisionmakers automatically think about people with disabilities when making policies







**QUESTIONS OR COMMENTS?**

**FABULOUS CARTOONS BY JOHN CALLAHAN**

