

- **To receive information re: future emergency policy & practice discussions & disability-related emergency information** from the California Disaster Coalition, sign up for mailing list at: [https://cftalk.org/mailman/listinfo/cadisastercoalition\\_cftalk.org](https://cftalk.org/mailman/listinfo/cadisastercoalition_cftalk.org)

- **Archived California Disaster Coalition emergency policy and practice discussions playlist:**

**[www.tiny.cc/dp1zuz](http://www.tiny.cc/dp1zuz)**

# Emergency Registries: A Misleading, Harmful & Non-inclusive Fix Part [1] 9/8/22 & Part [2] 10/13/22

California Foundation for Independent Living Centers, Cal  
Disaster Coalition - Monthly Emergency policy & practice  
discussions

- **Panel:**

- Moderator: Shaylin Sluzalis, Co-Executive Director, The Partnership for Inclusive Disaster Strategies
- Alexandra Enders, Consultant
- June Isaacson Kailes, Disability Policy Consultant
- Marcie Roth, Executive Director, World Institute on Disability

# **Registries (narrowed discussion focus):**

- **Sometimes referred to as “special needs” registries or registries for disabled people  
Used primarily by the government as disaster response & planning tools**

# Poll

- Are you somebody who manages a registry?
  - Yes, no
- Is there a registry in your area?
  - Yes, no, don't know
- Have you signed up for a registry ?
  - Yes, no,
- Have you personally been helped by a registry response?
  - Yes, no,

# Objectives:

- **To do review & recommend better options:**
  - Why are registries promoted as good practice & model interventions?
  - What harm can registries cause?
  - What are better options than registries?
- - Part 2 10/13/22
  - Are registries an effective planning tool
  - Evidence of impact & outcomes
  - What are the research questions

**Why are registries  
promoted as good  
practice & model  
interventions?**

- **Emergency managers seem to think that special needs registries work, even though there is no objective evaluation about how they work, if they work, or what works, & when. Additionally, special needs registries are based on a lot of false assumptions that typically go unchallenged. E.g., everyone with an access/functional need will register;**
- **From a voluntary registrant's perspective, any emergency registry is a tool for managing personal risk. From a responder's perspective, a registry is a tool for locating a person in danger & connecting them with needed resources. The details of how this actually works varies widely.**
- **Registries typically focus on specific registrant needs in any disruption. They typically lump together emergencies & disasters.**



# Emergency versus Disaster

- An **emergency** is an urgent, sudden, & serious event or an unexpected change in conditions that needs immediate action to resolve harm or prevent imminent danger to life, health, or property.
- An emergency is usually a small-scale, local incident that is handled quickly using local resources.

# Emergency versus Disaster

- **Disasters** are severe disruptions to the functioning of a community that exceeds its capacity to cope using its resources.
- A disaster is a large-scale, widespread event that may cross geographic & political boundaries. A disaster requires coordinated action across multiple entities & levels of government to resolve; it may be natural (floods, wildfires, or human-cause (war, terrorist attacks); or technological (power outages, cyber-attacks).
- **Common to all definitions of disaster: the disruption overwhelms the ability of the affected communities to cope using their resources.**

**What harm  
can registries  
cause?**

**What are  
better options  
than  
registries?**

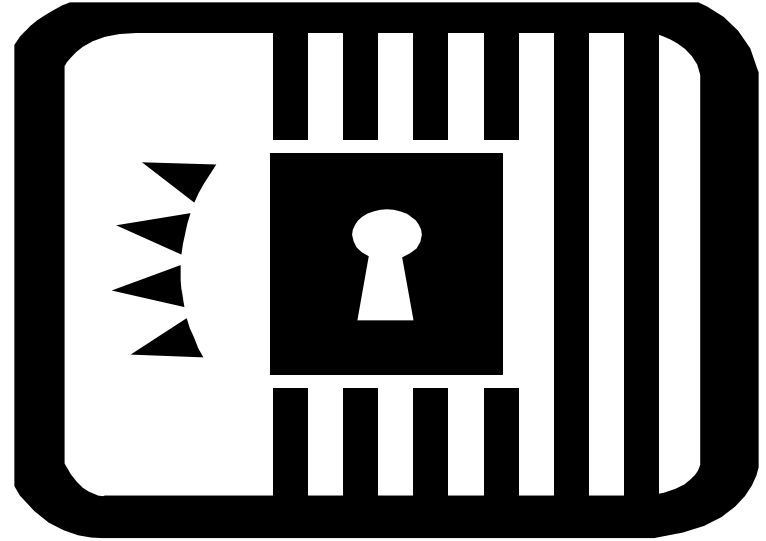
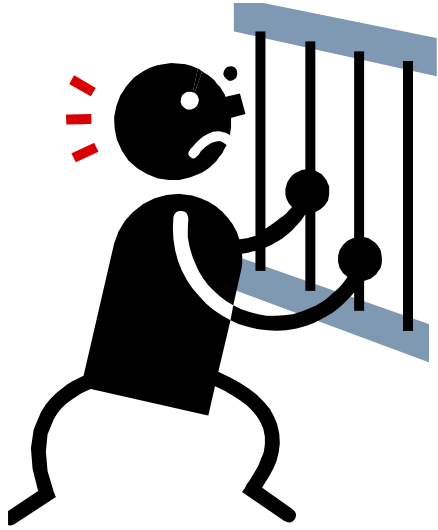
# Cover – Better Options

**1. Modernizing how people communicate if & when they need help**

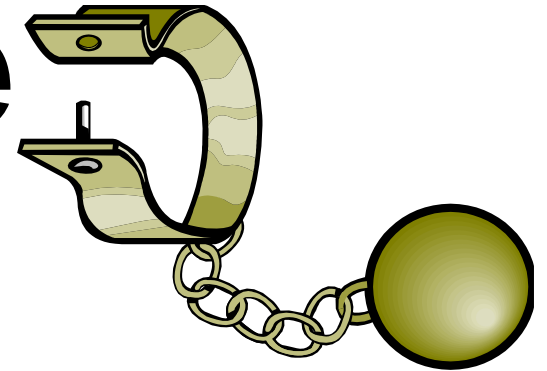
**2. Developing response capacity**

- **Strengthening, sustaining & embedding strong community partnerships**
- **Who, Why, What & How**

**3. Stronger transparency & honesty with public**



**Myth: People with disabilities are homebound!**



**[based on medical model]**

“Just because  
you know  
where I live,  
doesn't mean  
you know  
where I am!”  
June Kailes







# **Use & improve technology:**

- allows signaling for help via call, text, email, or button press**
- uses precise location services & sensor technologies**
- let people Use GPS apps that allow choosing contacts who can track their location in real-time & send an “I’m Safe” or “Need Help” message to a selected list**



# **PARTNERSHIPS - using broad community connections to build response capacity:**

- **Government**
- **Businesses**
- **CBOs – community-based organizations**
- **Self-organizing groups**
- **VOADS - Voluntary Agencies Active in Disasters**

# Partner planning & response roles:

- **Via contracts & agreements for -**
  - **Real & specific, not vague, personal emergency plans**
  - **Life-safety checks including providing:**
    - food, medications, supplies, backup power
    - evacuation assistance
      - from structures
      - Transportation out of & back to affected areas
    - personal assistant services
    - telehealth services
    - sheltering, temporary & permanent housing

# Transparency & honesty with the public

- Expose any disaster overpromise
- Clear & aimed at bursting magical thinking
  - there is a large amount of time when people are on their own!
  - 1<sup>st</sup> helpers are not 1<sup>st</sup> responders; they are nearby neighbors, friends, & family

# Symbolic planning

- **Guesses based on untried, undocumented, or unsuccessful practices. Symbolic plans lack specifics of who, what, where, when & how.**



**No magical thinking**

# the cavalry ain't comin'

The U.S. “ ... has a national disaster system that can mobilize an immediate & massive response in the aftermath of a catastrophe. .... this is a myth!!!”

Kelly McKinney (who had a leadership role in every major disaster in New York City for more than 20 years, from the 9/11 attacks to Superstorm Sandy to Covid-19)



# **Your Call to action :**

- **Making real > partner planning & shared response roles**
- **Hold government & other organizations accountable by speaking out, challenging & not accepting the unsupported use of registries that lack evidence of impact & outcomes.**

## Example:

- **Let people register in advance**
- ... people in the impacted areas get a call. Whether they need help or not,
- “people are very grateful,” ..... **“It makes them feel a little bit safer, a little bit less panicked.”**
- **AARP & FEMA published in 2022: AARP Disaster Resilience Tool Kit, A guide for how local leaders can reduce risks & better protect older adults**

# Discussion & Questions



# Resources

# Emergency Registries

<http://www.jik.com/d-rgt.html>

# Questions to ask from registrant's perspective, 1 of 4

## [1] IF I REGISTER:

- Will you just be alerting/warning me
- Will you be able to provide/deploy needed emergency resources?

## [2] IF I NEED EMERGENCY RESOURCES :

- How will the resources be available?
  - prior to the event (eg, backup generator, batteries, etc)
  - during the event (evacuation pickup vehicle; sheltering)
  - after the event (recovery assistance, well check, etc)

## Questions to ask from registrant's perspective, 2 of 4

### [3] WHAT AM I REGISTERING FOR?

- \* Response Coordination. Are you only coordinating a response, relaying information

- Response Resource Dispatch. Can you send/dispatch a response?  
(eg an evacuation vehicle)

- \* Response/Recovery Priority.

Triage: (sorting of and allocation of treatment according to a system of priorities)

Who decides? Who is doing the evaluation?

## Questions to ask from registrant's perspective, 3 of 4

(Geo-spatial relationship of need & resources to meet the needs)

[4] HOW WILL YOU KNOW WHERE I AM?

[5] WHERE IS THE RESPONSE COMING FROM?

(time, distance, cost, etc)



# Questions to ask from registrant's perspective 4 of 4

## [6] HOW ARE WE COMMUNICATING?

- Is there Two Way Communication?
- How do I let you know help has not arrived?
- How do I let you know my situation has changed? (eg, I no longer need assistance)
- How do you let me know the situation has changed?

## [7] FOLLOW-THROUGH/OUTCOME

- How will you know my needs have been addressed?
- How will you know if I need additional assistance?