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
• Archived California Disaster Coalition emergency policy and practice discussions playlist:

www.tiny.cc/dp1zuz
Emergency Registries: A Misleading, Harmful & Non-inclusive Fix

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
It looks like you’ve taken a hard fall.

I’m OK
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!
  • 1st helpers are not 1st 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 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?