From: June Isaacson Kailes, Disability Policy Consultant

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Comments: City of Los Angeles Commission on Disability 6/12/25 Public Hearing on <mark>emergency evacuation policies, procedures, and services for people with disabilities in Greater Los Angeles.</mark>

I am June Isaacson Kailes, Disability Policy Consultant. I'm based in Los Angeles and have lifelong lived disability experience. I'm recognized for my decades of extensive work as an innovator, studying, writing about, consulting on, and training others in the efficacy of disaster registries for people with disabilities. http://www.jik.com/d-bio.html

I focus on replacing the ambiguous aspects of disability etiquette, sensitivity, awareness, and legal compliance with maximum impact, practices, and measurable skill sets. I work with clients to build critical disability competencies and capabilities.

 I translate the laws and regulations into clear, actionable, detailed, and sustainable building blocks and tools that close service gaps, prevent civil rights violations, remove barriers, inequities, and disparities. I use "how, who, what, where, when, and why, to get physical, programmatic, communication, and equipment access right!

<mark>These comments and recommendations focus on:</mark>
- <mark>**Terms**</mark>
- <mark>**Registries' fatal flaws**</mark>
- <mark>**Questions to ask before deciding to develop and sustain a registry**</mark>
- <mark>**Alternative solutions to registries for more effective planning, response, and recovery**</mark>

Terms:

These comments are not aimed at small local events, which are typically effectively dealt with using available response resources. Such incidents include house fires, a downed power line, and vehicle accidents.

The comments primarily focus on the use of registries in disaster situations. A disaster is a large-scale, widespread event that may cross geographic and political boundaries and overwhelm the ability of the affected communities to cope using their resources. It requires coordinated action across multiple entities and levels of government to resolve. The disaster could be natural (floods, wildfires, earthquakes), human-caused (war, terrorist attacks), or technological (power outages, cyberattacks). The focus is not on small local events that are effectively handled using available response resources. Such incidents include house fires, downed power lines, and vehicle accidents, but rather larger disasters.

Registries are government programs that collect information about individuals with disabilities, typically comprising a database of individuals who sign up and meet specific eligibility requirements for receiving emergency response services based on their needs (See Resource below #6).

Registries fatal flaws

In my decades of professional experience and that of my subject matter expert colleagues (https://www.caloes.ca.gov/wp-content/uploads/AFN/Documents/General/CalOES-Voluntary-Disaster-Registry-Planning-Guidance-1.pdf),

(https://disasterstrategies.org/redirecting-emergency-registries-community-driven-solutions), registries are:

- dangerous, Band-Aid, magical thinking, check the box, short-sighted, shallow, non-solutions. Registries as solutions

used to placate and "keep us (people with disabilities) APPEASED and quiet! Emergency services have claimed, "Don't worry, we've got this. We'll take care of the disability problem." Just sign up for the registry. This "we know best" attitude devalues and ignores the lived experience (See Resources below #7,10).

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- They are like stubborn weeds, continuing to emerge despite their repeated failures.

==We owe it to ourselves and those who come after us not to be seduced into accepting and endorsing a registry solution.== Registries may check a box, but real safety and real resilience come from doing the hard planning work. Not checking a box. *As American journalist and scholar H.L. Mencken said,* ==**_"For every complex problem, there is an answer that is clear, simple, and wrong."_**==

==**Questions to ask before deciding to develop and sustain a registry:**==

Why choose to repeat failures?

Los Angeles County operated the Specific Needs Awareness Planning (SNAP) program. SNAP was an internet-based registry designed to assist residents with disabilities during emergencies. It was discontinued in 2016 due to challenges such as high maintenance costs, low participation rates, outdated software, and limited effectiveness in emergency planning.
https://file.lacounty.gov/SDSInter/bos/supdocs/100678.pdf

In 2004, the Los Angeles County Office of Emergency Management "…conducted research on the costs of developing and implementing a voluntary registry. According to this research, a registry program in LA would require 14 full- time staff, including 10 analysts, two employees to do geographic information system (GIS) mapping, and two administrative assistants. The total cost was estimated at just under $1.4 million per year (adjusted for inflation using the Consumer Price Index, that would be the equivalent to approximately 2,453,150 in 2025) for the first three years of the program, with two-thirds of the funds going towards staff and the remaining one-third for technology." https://grandjury.co.la.ca.us/gjury04-05 (2004–2005 Los Angeles County Civil Grand Jury Final Report (PDF)).

How will the fatal flaws of registries be addressed? How do you justify being committed to a registry when:

- They promote unrealistic expectations and a false sense of security for registrants that lead to dangerous situations and sometimes death. s "If I'm on the list, I'll get help." This undermines personal preparedness. Disclaimers are often ignored, regardless of how clear and strong they are, because **p**eople still believe the registry guarantees help. Registries divert attention away from personal preparedness (See Resource #).

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- They over-promise,

- They lack outcome and impact evidence, are misleading, and ignore the fact of repeated failures. Investigations point to their inability to work during disasters. Decades of media stories have repeatedly exposed failures in the use of registries for people with disabilities in large emergencies. Registry repeated

failures in big emergencies are well documented in *Texas, Florida, and California* (See Resource #).

- They give a *dangerous impression* of preparedness that fails in practice.
- <mark>They are based on outdated medical models, assuming people with disabilities are sick or homebound and easy to locate</mark>, that is

  o <mark>Knowing where I live doesn't tell you where I am</mark>
    o Knowing someone's home address does not mean you know where they are during an emergency.
    o People are mobile, live diverse and complex lives.
    o Registries fail to consider that real-world needs vary and shift during emergencies.

They distort the perception of need (based only on the few that sign up), thus minimizing the scope of required services and misinforming planning decisions. Data is often incomplete and quickly outdated. Sign-up rates are *very low*, and the information has a short shelf life (See Resource below #8).

- Low signup rates because people:

  - Fear of being labeled or losing independence
  - Concerns over privacy and immigration status
  - Distrust in government follow-through
  - They know registries don't work

  o They waste limited resources — responders, planners, and community partners spend time chasing flawed data instead of building real capacity. Responder waste effort (calls, trips, and time) chasing bad addresses, calling disconnected numbers, and rerouting scarce staff.
  o They represent symbolic planning and magical thinking based on *untested and undocumented guesses* that deliver no real help.
  - (See Resource below #4,8).

Alternative solutions to registries for more effective planning, response, and recovery

Understanding the flaws in registries' assumptions and possibilities for better solutions and outcomes is the first step toward providing more effective support and safety for the diverse communities of people with disabilities and others with access and functional needs. Hold each other accountable for the partnerships, hard work, and problem-solving needed to create, embed, deliver, and sustain real impacts and outcomes. The time is now to make changes to help people protect their health, safety, and independence and successfully cope with and live through the increasing and inevitable disasters.

Engage with disaster services subject matter experts who have lived experience and decades of emergency services experience, including myself, as you pursue the hard work of operationalizing real solutions versus a registry.

- Stop making empty promises by being honest with the public about what can and cannot be done.
- Invest in the hard work of:
    - Real plans and REAL partnerships- work at incorporating the specifics focused on the who, what, where, when, and how
        - Deployable response capacity
        - Inclusive communication systems for when people actually need help
        - Developing and sustaining partnerships with government, business, and community-based organizations
- Use of better planning tools — like census data, community mapping, and local engagement — that reflect real need projections

Contract with community-based organizations and businesses to help people create **personal preparedness plans** (See Resources below #1,2,3,5,10).

Resources to ==use for solution guidance:==

1 [Making Transit Evacuation Real for All (Podcast 21 minutes)](#) (2025) [Note: takes a few minutes to load.] NEW
Featuring June Kailes, a disability policy consultant who offers ==guidance on improving emergency transit evacuation plans, particularly for individuals with disabilities. Kailes emphasizes moving beyond vague language and theoretical plans towards clear, actionable, and measurable strategies.== She stresses the importance of specific details in planning documents and contracts with community organizations, advocating for honest public communication regarding response limitations and the necessity of personal preparedness. The discussion highlights the failures of relying on emergency registries and promotes neighbor-to-neighbor support and realistic expectations during disasters. Ultimately, the material ==encourages a cycle of planning, testing, analysis, and revision to strengthen emergency response capabilities for disproportionately impacted populations.== Resources and tools are mentioned to aid in assessing gaps and developing more effective evacuation strategies.

[**Transit Evacuation Plans for People with Disabilities: Key Integration Details**](#) **(April 2025) NEW** ==A tool for people and teams responsible for developing, responding, maintaining, testing, and revising emergency transit evacuation services and their associated plans, annexes, processes, procedures, protocols, policies, job aids, field operation guides, and training. Use this tool==

- ==for a realistic and honest assessment of gaps==
- ==to collectively identify opportunities for improvement==
- ==to identify individuals who have responsibility, authority, and resources to lead the effort on specific elements needing attention.==
- ==problem-solving and track progress==

==**Disability Emergency Personal Evacuation Transportation Planning** (April 2025) NEW Focuses on disability-related details of preparing for the many hazards that can involve leaving a disaster-affected area.==

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2 [Building Trust in Emergency Planning and Response Podcast](#) (2025) 21 minutes.

- o Corrections:
  - To access these two new 2025 documents:
    - **Transit Evacuation Plans for People with Disabilities: Key Integration Details**
    - **Disability Emergency Personal Evacuation Transportation Planning**
    - Go to **https://disasterstrategies.org and look for "USEFUL INFO"**
  - **The Los Angeles County link is https://recovery.lacounty.gov**
- o **[Trust in Emergency Management Dashboard Quiz](#)** (2025)
- o **[Trust versus No Trust Examples in Emergency Management](#)** (2025)
- o **[Your Role in Strengthening Trust in Emergency Management](#)** (2025) Slides

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Below is an AI-generated summary (all links have been checked and verified by June Kailes) of solution-based guidance that represents the hard work required to provide a real solution for transit evacuation planning and services.

June Isaacson Kailes is a renowned disability policy consultant whose extensive work critically examines the use of disaster registries for people with disabilities. She emphasizes the potential shortcomings of such registries and advocates for more

effective, inclusive emergency planning strategies. Below is a curated list of her key contributions on this topic, each accompanied by a brief annotation and direct link:

🗞 Core Publications and Tools

📰 Articles and Commentary

3. **[<mark>Beyond Registries: Better Solutions for People With Disabilitie</mark>s](https://www.domprep.com/articles/beyond-registries-better-solutions-for-people-with-disabilities)**
   An article that critiques the reliance on registries and proposes alternative methods for ensuring the safety and inclusion of people with disabilities during emergencies.

4 **[Access and Functional Needs Emergency Registry Assessment Tool](https://www.jik.com/d-rgt-tool.html)**
   A <mark>practical tool designed to help jurisdictions evaluate the viability and effectiveness of implementing or maintaining emergency registries, emphasizing the importance of aligning registrant needs with available resources</mark>.

5. **[Redirecting Emergency Registries: Community Driven Solutions](https://disasterstrategies.org/redirecting-emergency-registries-community-driven-solutions /)**
   This piece emphasizes the need for community engagement and collaboration with disability-led organizations to develop more effective emergency response strategies.

6 **[Emergency Registries for People with Disabilities and Others with Access and Functional Needs](https://www.jik.com/d-rgt.html)**

This comprehensive resource explores the complexities of emergency registries, highlighting the discrepancies between registrant expectations and responder capabilities. It also discusses the potential pitfalls of relying solely on registries for disaster preparedness.

7 **[Emergency Registries 2018)](https://www.jik.com/pubs/EmergencyRegistries.pdf)** This detailed report examines real-world applications of registries during disasters like Hurricanes Harvey and Irma, revealing significant gaps between registry data and actual emergency response effectiveness.

8. **[Stakeholder Opinions of Access and Functional Needs Emergency Registries](https://www.jik.com/d-rgt-opin.html)   This compilation presents diverse perspectives from disability communities and emergency planners, discussing concerns about privacy, data accuracy, and the potential false sense of security that registries may provide.

9 **[Flowchart: Deciding to Use an Access and Functional Needs Emergency Registry](https://www.jik.com/d-rgt-flowchart.html)**
   A visual guide that assists planners in determining the appropriateness of implementing a registry, considering factors like purpose, scope, and resource availability.

🎞 Presentations and Webinars

10 **[Emergency Registries: A Misleading, Harmful and Non-Inclusive Fix (Part 1)](https://www.youtube.com/watch?v=mexNCwt1Iw8)**
        This webinar discusses the limitations of emergency registries and advocates for more inclusive and effective disaster planning strategies.

(Part 2)](https://www.youtube.com/watch?v=oRyvS9TG1QQ)**

   Continuing from Part 1, this session delves deeper into alternative solutions and the importance of community-driven approaches to emergency preparedness.

🗃 Additional Resources

11. **[Access and Functional Needs Emergency Registry Websites](https://www.jik.com/d-rgt-links.html)**
   A curated list of existing emergency registries across various jurisdictions, providing insights into their structures and implementations.

12. **[Disaster Resources for People with Disabilities and Others with Access and Functional Needs](https://www.jik.com/disaster.html)**
   A comprehensive collection of resources, including guides, checklists, and tools aimed at enhancing disaster preparedness and response for individuals with disabilities.