Pacific ADA Center

ADA National Network — Information, Guidance, and Training on the Americans with Disabilities Act

Great Lakes ADA Center

Emergency Management and Preparedness Session
"Registries: It's not about the list!"

The Session is Scheduled to begin at 2:00 pm ET
We will be testing sound quality periodically

Telephone Option: 712-432-3100 Access Code: 930098 (not a toll free #)

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2

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3

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September 11, 2014

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4

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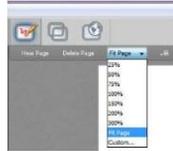
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September 11, 2014

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7

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9

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September 11, 2014

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10

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"It's Not About the List" – Some Research Derived Thoughts Regarding Emergency Assistance Registries

Dr. Paul Hewett

Center for Integrated Emergency Preparedness

Decision and Information Sciences

The not hidden agenda

- Some background on "Special Needs" registries

- A case study

- What the case study tells us

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12

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September 11, 2014

What is an "Emergency Assistance Registry"

- A list or set of lists of individuals that a community uses to plan for and direct emergency services to its enrollees.
- Usually, there is an organization responsible for coordinating or providing disaster services maintains the list.
- The list's data elements consist of:
  - enrollee names, addresses, and contact information
  - enrollee disabilities or access or functional needs selected from a community-generated set of characteristics.
- The registry may take the form of indexed card decks, spreadsheets, tables, electronic databases, or complex geographic information systems.

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13

Why registries?

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Court Cases

State Statutes

Disability Organizations

Policy and Interest Groups

Researchers

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14

Who are you registering?

Communication
Medical care
Independence
Supervision
Transportation

Access & Functional Needs

One can have these
Without this
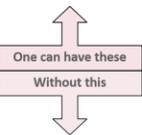
Disability

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15

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What the research says about registry use in the U.S. – Target population

- People with special needs
- People needing evacuation assistance
- Children home alone
- People with medical needs
- People with social (e.g., C-MIST) needs
- Economic disadvantage
- Language and literacy
- Individuals who require access to electricity
- The frail elderly

16

What the research says about registry use in the U.S. - Purpose

- Providing enrollees warning and other emergency information
- Checking on enrollee status pre- and post-event
- Providing evacuation or transportation assistance
- Targeting preparedness efforts
- Identifying enrollee locations for planning

17

What the research says about registry use in the U.S. – Responsible agency

- Emergency Management Agency
- Utilities (collecting information)
- Fire Department
- Paratransit Agency
- Department of Health

18

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What the research says about registry use in the U.S. - Registration methods

- Forms or cards (Return mail, email, or fax)
- Online (Web-forms)
- Telephone
- Service provider registrations
- "Lists-of-lists"

19

What the research says about registry use in the U.S. - Information storage

- Purpose designed GIS
- Crisis information management systems (e.g., WebEOC)
- Business software spreadsheets or databases (e.g., Microsoft Excel or Access)
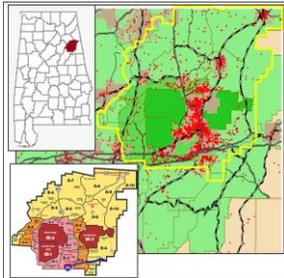- Agency created databases
- Card decks

20

The case study

Calhoun County, Alabama

Registry foot print and enrollee locations circa 2001

- Documented method of establishing the registry (Metz et al. 2002)
- 10 years of episodic and running archives
- Specific technological hazard plus all natural hazards.
- Used multiple registration methods
- Used single organization and an organizational network to operate the registry.

21

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What the community did...

- Determined the registry's purpose
- Set up the registry's administration and information collection processes
- Collected information
- Compared information with primary hazard
- Determined what services would be provided
- Determined individual accommodations based upon reported needs
- Follow-up

22

Registration methods

- Emergency management research recommends return mail surveys, web-based survey, service provider referral, and list-of-lists as registration methods.
  - All methods were attempted at some point during the period examined
  - Organizational network members indicated they had a larger role in registration than supported by registry data.
  - Beliefs about HIPAA caused service providers to not share their lists or do referrals.
  - No web-based registrations during the three years it was available

23

Outcome: Ten-year enrollment trends

- Initial registration in 2000 was 3021
- 50% turn-over each year
- Registrations trended downward linearly each year, so that by 2010 there were only 1632 registrations.
- Reasons for not reregistering were tracked:
  - 2004 to 2007: 39.5% no longer need assistance / 29.4% deaths.
  - 2008 to 2010: 4.7% no longer need assistance / 68.0% deaths
  - Focusing service efforts on preparedness works!

24

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Enrollment as a percentage of the population

Census Year	General Population	Disability Population	Enrolled Population	Enrolled Population as a Percentage of General Population	Enrolled Population as a Percentage of Disability Population
2000[†]	112,249	25,861	3021	2.69	11.68
2010	117,641	21,295	1632	1.39	7.66

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25

The importance of purpose

- How will the information be used?
- Influences registry administration and delivery of services
- How will it aid in the planning for and delivery of services?
- Can the information be obtained another way?

"My first question is what's the purpose [for the registry]? What's the purpose? What are you telling these folks when you register them?"

"If you are going to establish a registry and have not thought out how you are going to use it, how you are going to maintain it, and how you brought value back to the person who gave you the information it is going to die on the vine…"

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26

Hazard interpretation affects registry focus

"…honestly, early on, we were kind of thinking we could suit-up first responders and get [the special needs population] out."

"When we first ran the special population [planner software] and pulled up that map, and it showed the number of people located in the pink zone, I mean light bulbs started going off immediately and we had a big problem. It was a huge problem. So, we knew we needed to come up with something very unique for those people close in and then take care of the people in the outlying area."

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27

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Social contract/obligation

- Most registries indicate that there is no guarantee for services
  - Just like any other government provided service, it is a social contract/obligation or political promise **UNLESS…**
  - The registrant has a disability – then under the ADA the government providing the service MUST provide a reasonable accommodation to achieve same access to the service
  - Goes back to purpose
  - What is being provide to the populations at large, what is the expectation (issue of self-preparedness)

"When we started getting [registration forms] in, it was kind of interesting, because we had the conversation "ok we identified those special needs people, what are we going to do with them?" Because, now something is expected of us."

An organization's role defines its expectations for the registry's function within the community

- Disaster-centric organizations saw the registry as reinforcing individual preparedness

  "A registry was never designed for us to gather all of the information for the government to come and help you. This is not the 82nd airborne. We do not have helicopters where people are going to dive in there and rescue you. [The registries purpose is] to identify potential risks and to provide alternatives so you can help yourself. " (Public Official)

- Service-centric organizations saw the registry as a way for people who cannot help themselves to receive assistance

  "I expected [the registry] to be used as in case of emergency they would check to see if [those in need] were taken care of… I kind of believe that the people at that FEMA … they would have people in the communities that had signed up for that duty to go and check." (Individual who raised awareness for the registry)

For a registry to work everyone must buy into the final product

"If you are going to establish a registry you must let people know how you are going to use it. You must go out and get buy in from all of those potential support agents. You have to get buy in from the religious leaders. You have to get buy in from the city and the political leaders. You have to get buy in from the first responders and receivers. You have to get them to buy in that there is value there. If any one of those four groups don't buy in the success of that registry being established and being sold may be negated. "

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Need or disability were not the only reasons for enrolling

- People put themselves on the registry so they can feel a sense of connectedness to others in the community

  "I think a lot of that had to do with they want to be heard. The residents that registered with us, they wanted us to know that they were there. A lot of our responders didn't even know that these residents even had any special needs because there wasn't an interest there. When you have a registry of residents like we did and you have the contact that we did then we contact them on a regular basis, they become more than just a number. They become a person." (Interviewee who worked on registering respondents)

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31

Information quality is dependent upon many factors

- Much depends upon how the community defines who they are targeting for enrollment.
- Words mean something:
  - "Can't see" vs. "Severe Vision Problem" vs. "Blind, Legally Blind, Partially Blind, Night Blind"
- Information provided by surrogates (family member, guardian) often reflects their view of need, not the enrollee's.
- The elderly's views of self-sufficiency, self-esteem, and pride often lead to non-enrollment:

  "Senior citizens don't necessarily classify themselves as being special needs. They think special needs are that, somebody with a special need. Just because they are old does not mean they have a special need. So they were reluctant to put their name on the list because they thought there were other people who needed to be on there."

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32

Contact Information

Paul L. Hewett Jr., Ph.D.
Deputy Director, Center for Integrated
Emergency Preparedness

Decision and Information Sciences Division
Argonne National Laboratory
1301 Beaumont Court
Forest Hill, MD 21050-2408
www.dis.anl.gov/groups/ciep.html
www.anl.gov

240-426-1266 office/mobile
plhewett@anl.gov

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33

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Further Resource

Emergency Registries for People with Access & Functional Needs

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

- What is a Registry?
- Emergency Registry Assessment Tool
- Flowchart: Deciding to Use an Access & Functional Needs Emergency Registry
- Stakeholder Opinions of Registries
- Registry Websites
- Papers, Presentations, Webinars, Resources

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34

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Questions?

35

Emergency Management and Preparedness - Inclusion of Persons with Disabilities Webinar Series - 2014-15

- ADA Nat'l Network (Pacific ADA Center) teaming with FEMA's ODIC
- Monthly webinars – 2nd Thursday
- 2:30pm ET, 1:30pm CT, 12:30pm MT, 11:30am PT, 8:30am HT
- ADAPresentations.org to signup

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36

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- Lineup includes:
  - 6 promising practices
  - 6 sessions on important topics
  - First one will be October 9: Effective Communications for Deaf and Hard of Hearing in Emergencies – Candice Alder, Colorado Commission for the Deaf and Hard of Hearing

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37

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