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BEST PRACTICE

Special Needs Registries: Registration Processes

PURPOSE

This Best Practice describes processes used to register individuals in special needs registries, including information collection and dissemination.

SUMMARY

The registration process is critical for the success of a special needs registry. This process presents an opportunity for jurisdictions to provide information to and solicit information from registrants. In many cases, this exchange of information happens only once per year. Jurisdictions must use this opportunity to communicate essential information about the registry to individuals. Jurisdictions must also have an effective method for soliciting information from registrants.

About This Best Practice

This Best Practice is part of the Special Needs Registries series. It describes registration practices employed by various jurisdictions for special needs registries and consists of the following sections:

- Information Provided During the Registration Process
- How to Provide Information
- Information Solicited
- Ensuring Consent

Information Provided During the Registration Process

Jurisdictions must ensure that specific information about special needs registries is communicated meaningfully and effectively to potential registrants. For example, jurisdictions should communicate what services may be available to registrants as a result of participating in the registry. They should also

See FEMA's [Interim Emergency Management Planning Guide for Special Needs Populations](#), Appendix E, for more registry guidance.

inform registrants that participation in the registry is voluntary and that information submitted to the registry is confidential. The registration process presents an opportunity for jurisdictions to provide this information to potential registrants. Information that jurisdictions should communicate includes:

- Purpose of the registry;
- Guarantee of service or assistance;
- Contact information for the registry;
- Voluntariness of the registry;
- Eligibility for participation in the registry;
- Reregistration and information updates;
- Preparedness education; and

- Pet policies.

Purpose of the Registry

Potential registrants must have a clear understanding of what participation in the registry entails and what assistance may be available to them before, during, and after an incident. This helps to manage registrants' expectations and can help individuals determine if they should register based on whether the assistance provided would be of use to them.

Jurisdictions can use the registration process to communicate the purpose of the registry to registrants. For example, the Orange County, North Carolina, Department of Social Services' Special Needs Registry application form contains a list of actions that Orange County will undertake on behalf of registrants in the event of a disaster. FEMA's *Interim Emergency Management Planning Guide for Special Needs Populations* recommends that jurisdictions ensure potential registrants have realistic expectations about the services offered by the registry.

Guarantee of Service or Assistance

Jurisdictions should inform potential registrants that participation in the registry is not a guarantee of services or assistance. Jurisdictions should communicate that an emergency number, such as 9-1-1, should still be used if a registrant requires emergency assistance. Further, jurisdictions should emphasize that registries do not replace personal preparedness plans. Dane County, Wisconsin, Emergency Management's Disaster Voluntary Assistance Registry emphasizes that participation in the registry assists emergency management personnel and local officials with meeting the community's emergency needs, but it does not guarantee particular emergency services for individuals.

Registration forms for the following jurisdictions' special needs registries are available on LLIS.gov:

- [Dane County, Wisconsin](#)
- [Orange County, North Carolina](#)
- [Osceola County, Florida](#)
- [Pinellas County, Florida](#)
- [Volusia County, Florida](#)

Contact Information for the Registry

Jurisdictions should provide contact information for personnel who participate in operating the registry. This will ensure that individuals with questions about the registration process, registry eligibility, or procedures for updating information are able to contact the appropriate person.

Voluntariness of the Registry

Jurisdictions should inform potential registrants that participation in the registry is voluntary. Many registration forms request that individuals submit personal background and medical information. Potential registrants should understand that they are not required to submit this information or to participate in the registry.

Eligibility for Participation in the Registry

Jurisdictions should provide a description of who is eligible for the registry. They should also provide information about circumstances that may preclude individuals from certain assistance, such as living in an assisted living facility or nursing home. For example, Orange County, North Carolina, informs registrants on its registration form that eligibility is determined on a case-by-case basis and generally includes those who do not require hospital care but who need assistance that cannot be provided by public shelter staff. The registration form provides a list of examples of individuals who may be eligible for the registry. In general, jurisdictions should provide information about eligibility early in the registration process so that individuals do not spend time applying to registries for which they are not eligible.

Reregistration and Information Updates

Jurisdictions should provide proper notification about how often individuals need to reregister or update their information. For example, Osceola County, Florida, Emergency Management's Special Needs Registry registration form clearly states that registrants must apply for the registry annually. Dane County, Wisconsin, Emergency Management's Disaster Assistance Voluntary Registry registration form requires registrants to initial next to a statement explaining that they must update their information on an annual basis or as soon as their information changes.

Jurisdictions should also consider explaining the process for reregistering or updating information. For example, the Volusia County, Florida, Special Needs Registry registration form informs registrants that they will receive an annual notification to reregister for the program. It also explains that registrants must resubmit a registration form if they need to update their information before the annual reregistration process.

Preparedness Education

Jurisdictions can use the registration process as an opportunity to educate registrants about basic preparedness. Some jurisdictions provide recommended steps that registrants should take prior to evacuating to a shelter. The Volusia County, Florida, Special Needs Shelters Program registration form includes a list of items that registrants should bring with them to a shelter and reminds registrants of tasks they should complete before evacuating, such as notifying family and friends where they will be during a disaster. Similarly, Monroe County, Florida, Social Services' Special Needs Registry provides a document entitled *Monroe County Special Needs Registry Sheltering Information* on its Special Needs Registry Web page that includes information about what individuals with disabilities and other access and functional needs should bring with them to shelters. The Delaware County, Ohio, Special Needs Registry uses the registration process to promote the importance of personal preparedness plans and to provide registrants with fire safety information.

[Monroe County, Florida, Special Needs Registry Sheltering Information](#) is available on *LLIS.gov*.

Pet Policies

During the registration process, jurisdictions should consider communicating shelter policies for pets. Jurisdictions can also provide registrants with information about how they should prepare their pets for an evacuation. For example, Osceola County, Florida, Emergency Management's Special Needs Registry application form states that pets are not allowed in special needs shelters. However, it informs registrants that personnel will transport a registrant's pet(s) to a pet shelter if the registrant is unable to make other arrangements. Monroe County, Florida, Social Services' Special Needs Registry provides a pet sheltering form alongside the registry application form for individuals on its Special Needs Registry Web page. Pinellas County, Florida, Emergency Management's Evacuation Assistance Program registration form provides registrants with a number to call for assistance with their pets.

How to Provide Information

The registration process presents various options for jurisdictions to provide information to potential and current registrants. Jurisdictions can use registration forms, informational brochures, or their special needs registry Web site to communicate information such as legal procedures or registry policies with potential registrants.

Registration Forms

The most common means of providing information to individuals during the registration process is a registration form. Jurisdictions can attach additional pages, such as a Frequently Asked Questions page, to their registration forms. Additionally, jurisdictions can require that registrants sign the registration form acknowledging that they have read and understood all parts of the form. For example, Dane County, Wisconsin, Emergency Management's Disaster Assistance Voluntary Registry registration form consists of four pages including an information intake form, a list of registry policies and procedures that registrants must initial, and an authorization form to release information that registrants must sign.

Informational Brochures

Some jurisdictions choose to produce informational brochures to provide registrants with information about the registry. Jurisdictions can make these available in hard copy along with registration forms or they can provide electronic copies on the registry Web site. For example, the Fairfax County, Virginia, Office of Emergency Management's Special Needs Registry provides electronic brochures that contain information about the purpose of the registry and where to get more information about the registry.

Special Needs Registry Web Site

Many jurisdictions provide information about their registries through a Web site. This allows jurisdictions to present pertinent information and additional resources in a centralized location.

Information Solicited

Jurisdictions face the challenge of ensuring that they collect the necessary information from registrants during the registration process without requiring so much information that individuals are deterred from participating in the registry.

Personal and Contact Information

Registration forms may solicit basic personal information such as:

- Name;
- Date of birth; and
- Physical description including height, weight, gender, race, and hair and eye color.

Forms may also ask what the individual's primary language or form of communication is. Forms may request the registrant's contact information, including physical address and nearest intersection, phone number, and email address, if available. Forms may also collect

Special Needs Registry

Responsibilities

In order to meet the special needs of persons who would need assistance during evacuations and sheltering because of physical and mental handicaps, Florida statutes mandate that each local emergency management agency in the state maintain a registry of disabled persons located within the jurisdiction of the local agency.

The registration must identify those persons in need of assistance and plan for resource allocation to meet those identified needs.

Resources

- [2011 Registry Application Information](#)
- [Pet Sheltering Form](#)
- [Protected Health Information Form](#)
- [Acknowledgment of Receipt Form](#)
- [Disclosure of information Form](#)

Monroe County Special Needs Registry Sheltering Information

Individuals are eligible to be registered with the Special Needs Registry if they are 60 years of age or older, frail, elderly, medically needy, and/or disabled and are not served in or by a residential facility program. Eligible clients are required to complete and sign the Special Needs Registry Application as well as the HIPAA Disclosure of Information and HIPAA Privacy Act forms before they will be placed on the registry.

The Monroe County, Florida, Social Services' Special Needs Registry provides information about the registry and links to additional resources on its Web site.

information about other addresses where residents spend time if they are absent from their home address for a substantial part of the day. This would apply to individuals who work for long periods outside the home or who may be enrolled in adult day care or sheltered workshop settings.

Registration forms may request contact information for an emergency contact. Some registration forms ask for both local and non-local emergency contacts. Contact information may also be solicited for the individual's caregiver or person assisting the individual with completing the registration. This information is useful for contacting registrants before, during, or after disasters and for obtaining updates to information. Jurisdictions might also consider requesting contact information for an alternative contact. This person could be a friend or neighbor who would not be contacted for emergency purposes but who could provide information about the whereabouts of a registrant during an evacuation.

Registration forms may ask for a description of the registrant's residence. This includes questions about the registrant's type of residence, such as a condominium, house, or apartment, or if the residence has controlled access. In some jurisdictions, this information can be used to determine which registrants need to be evacuated. For example, registrants living in mobile homes or on boats might be evacuated before residents living in houses. It is also helpful to know whether the individual resides with other people.

Finally, jurisdictions should consider including questions that pertain to specific features or characteristics of that particular jurisdiction. For example, Monroe County, Florida, Social Services' Special Needs Registry registration form asks for an individual's location in reference to the nearest highway mile marker because one large stretch of highway spans the length of a portion of the jurisdiction.

Medical Background

Jurisdictions may collect medical background information if their registry operations require it. This information commonly includes cognitive, mental, and emotional conditions; vision, hearing, and mobility problems; difficulty breathing; difficulty communicating; allergy information; special dietary needs; medication information; equipment requirements; and other conditions related to medical history. Jurisdictions may also want to know if registrants are ambulatory or bedbound, if they require a wheelchair, and if they are oxygen-dependent. Registration forms can solicit medical information in various formats, including check boxes or a blank space for registrants to write in information. Check boxes allow for better readability but can restrict the amount of information registrants are able to provide. Registration forms may also solicit information about an individual's primary care physician and insurance.

Medical background information is useful for personnel providing evacuation assistance or other services to registrants. It also provides the jurisdiction with information about the number and type of resources and equipment required by its residents. For example, individuals who are bedbound or oxygen-dependent may require specific transportation means, such as an ambulance.

However, it is important to note that not all jurisdictions collect detailed medical information. Dane County, Wisconsin, Emergency Management's Disaster Assistance Voluntary Registry registration form specifically does not collect medical information to avoid Health Insurance Portability and Accountability Act issues. Instead, it focuses on the functional challenges related to evacuation, transportation, and communication.

Ability to Evacuate

Registration forms should ask the registrant about his or her ability to evacuate. Forms may have a separate section for these questions, or the questions may be combined with other sections (e.g., personal emergency planning section or personal information section). Also, answers to these questions may overlap with the medical background questionnaire section. Common questions include whether the registrant receives assistance from a caregiver, if the registrant needs to be notified of an evacuation, if the registrant needs transportation assistance, and if special needs sheltering may be required.

Personal Preparedness Plan

Registration forms should encourage registrants to develop their personal preparedness plan. This can urge registrants to consider what they will do if directed to stay at home during a disaster or to evacuate. If an evacuation is ordered, registrants' personal preparedness plans should address whether they will go to a shelter or will stay with family or friends during an evacuation and whether the registrants will be evacuating alone or with someone else, such as a caregiver or spouse.

Ensuring Consent

Jurisdictions should have procedures in place to obtain consent from registrants to release their information to hospitals, public safety workers or responders, and emergency management personnel and to accept the terms and conditions of registration. Many registration forms contain a signature page with specific language about what the registrant is agreeing to by signing the document. Dane County, Wisconsin, Emergency Management's Disaster Assistance Voluntary Registry registration form contains a bulleted list of items that registrants must agree to by initialing each item. Jurisdictions that provide online registration commonly include a check box at the bottom of the registration page that registrants must select before submitting their registration to designate their consent.

RESOURCES

References

Department of Homeland Security, Office for Civil Rights and Civil Liberties. *Individuals with Disabilities in Emergency Preparedness Annual Report 2005*. 21 Jul 2005.

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Department of Homeland Security, Office for Civil Rights and Civil Liberties and Federal Emergency Management Agency. *Interim Emergency Management Planning Guide for Special Needs Populations*. 15 Aug 2008.

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Jones, Nancy Lee. *The Americans with Disabilities Act and Emergency Preparedness and Response*. Library of Congress and Congressional Research Service. 21 Jul 2006.

<https://www.llis.dhs.gov/docdetails/details.do?contentID=31878>

Library of Congress. *Emergency Preparedness and Response for Individuals with Disabilities Act of 2005*. 16 Dec 2005.

<https://www.llis.dhs.gov/docdetails/details.do?contentID=22317>

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Steinhauer, Michael. Special Needs Planner, Dane County, Wisconsin, Department of Emergency Management. Interview with *Lessons Learned Information Sharing*, 18 Aug 2010.

Links

Dane County, Wisconsin, Emergency Management, Disaster Assistance Voluntary Registry.
<http://www.countyofdane.com/emergency/needs/registry.aspx>.

Delaware County, Ohio, Special Needs Registry.
<http://www.delcospecialneeds.com/>

Fairfax County, Virginia, Office of Emergency Management, Special Needs Registry.
<http://www.fairfaxcounty.gov/specialneeds/>

Monroe County, Florida, Social Services, Special Needs Registry.
<http://www.monroecounty-fl.gov/index.aspx?NID=148>

Orange County, North Carolina, Department of Social Services, Special Needs Registry/Shelters.
http://www.co.orange.nc.us/socsvcs/special_needs_registry.asp

Osceola County, Florida, Emergency Management, Shelters: Special Needs Program.
http://www.osceola.org/emergencymanagement/120-3779-3781/special_needs_program.cfm

Pinellas County, Florida, Emergency Management, Hurricane Preparedness: Special Needs.
<http://www.pinellascounty.org/emergency/specialneeds.htm>

Volusia County, Florida, Special Needs Shelters (SNS).
<http://www.volusia.org/storm/specialneeds.htm>

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