# 3.4 Registries Fact Sheet

**Purpose:** The fact sheet provides an overview of research findings and pros and cons on registries as they relate to the roles and relationships between emergency managers, transportation, and vulnerable populations. This tool is not a policy recommendation on registries. Opinions on registries vary from ardent advocates to vocal opponents; descriptions and understanding of registries also vary.

**Directions:** Following a review of registry types (below) and local threats, conditions, and resources, network members may decide that one or more of the following options may enhance local readiness. The letters H, M, and L indicate if the tool is high, medium, or low in a specific area. This is a good discussion tool and meeting agenda item.

| **Inclusive** | **Planning Utility** | **Title** | **Description** | **Pro** | **Con** |
| --- | --- | --- | --- | --- | --- |
| H | L | Universal Registries/ Emergency Alert Notification Systems | Anyone can sign up to get an emergency alert notification, on whatever device, and in whatever format that is available. Universal emergency alert systems include Reverse 911 calling and similar automated systems.Many locations have worked with people who are deaf, hard of hearing, and blind to develop and deploy alternative emergency alert systems, including lights, text messages, Braille message pads, bed shakers, and similar technologies. | Provides inclusive distribution of information regardless of location. Many communities are working to make technology fully accessible. | Does not provide information to the transportation and emergency managers as to vulnerabilities or additional assistance that may be needed. Assumes power and communication networks are intact. |
| M-H | M-H | Transportation to transportation “hubs” or shelters (with or without registry – usually without) | Many transit-based evacuation plans, including those in Florida, New Orleans, and Houston do not require “advance registration” to assemble at common publicized pick up points to be transported to safe havens. Once there, clients may be required to register, either to gain access to a shelter or to be transported farther away to a safer haven. | Inclusive for participation, large movements of people; requires planning, coordination, and public awareness. | Numbers are not known in advance; have to arrange for those who can’t get to pick up points. |
| M-H | H-M | Automated Registries/ Databases | Most states and many counties have extensive databases of clients for Meals on Wheels, home help, durable medical equipment, etc. Nevada, for example, requests clients to sign a waiver that the information can be used for emergency contact, though still within the confines of HIPAA regulations. | Can provide reasonable advance estimates for needed transportation and emergency management resources (within HIPAA). Great asset for network planning. | Many individuals are likely to require case management; advance emergency planning per network planning. |
| L | M | Voluntary Registries | Texas and Florida (and others) have established 3-1-1 and 2-1-1 programs to ask people who may need additional assistance in emergencies to register. The number of people registering in advance is typically very small, though it is advertised through mobility programs, home health care programs, and other venues. Once an event is imminent, on-the-fly registrations typically soar; for example, in Houston, only hundreds were registered prior to Hurricane Ike, but more than 15,000 people with special needs or medical needs were assisted through SETTRAC.  A comprehensive registry for people with functional needs that may need to be evacuated should address:   * Medical equipment needs * Companion caregiver/ attendant * Service animal * Household pet * Communication needs | Provides a “soft” foundation for transportation and emergency management planning.  In the cases of people who are isolated, homebound, elderly, or others with severe limitations on mobility, this may be the only viable alternative until an effective, comprehensive, and cohesive community-based support network is established and tested. | Labor-intensive to update and keep updated. People go to work, move, die, or the situation for which they originally registered may change, requiring a different level of assistance. The process of calling or making other contacts to verify the situation is painstaking and expensive. Also, people are not always at home.  Advocates and critics of registries cite the reluctance of people to sign up for fear of being marked as vulnerable, legal status (for themselves or family members), authority, or losing independence. Others have a sense of invulnerability. Some are also afraid if they register and leave that they will not be able to return. |
| L | M-H | “Exceptional Circumstance” Special Medical Needs Registries | Houston (as part of its “Health, Mental Health and Medical Services” Function) has established a registry with 800 call-in numbers and individual registration numbers to track medical records and establish seamless connections for dialysis patients who must relocate across the state. They have also established safe havens for people in iron lungs (15 in Houston) at facilities in other locations where they can be transported with auxiliary equipment. | For its limited purpose, pertaining to a very small portion of the population, it is essential to managing care and saving lives. | It is very specialized and intense; its needs and successes may be seen as an example to be generalized to broader population groups. |

## Summary Lessons Learned about Registries:

Universal alert systems are valuable in areas with recurring notice and no-notice events. Other forms of registries MAY be appropriate in areas where the greatest threat is likely known well in advance (as in the case of hurricanes), and MAY be appropriate in areas prone to no-notice events, especially for those people who are homebound and likely under some level of medical care. Registries may be particularly useful for those with medical conditions requiring complex medical coordination across local and possibly state boundaries, such as people requiring dialysis or people in iron lungs.

Until an effective community network is established and tested, a registry MAY be appropriate for people with medical needs who are likely to require assistance to leave their home (including people needing supervision, such as people with cognitive disabilities or with multiple compounding disabilities). Registries may not be as useful and may be counterproductive for those who simply need transportation, whether lift-equipped or regular.

Decisions about registries should be made collaboratively with people who have functional needs or their representatives to ensure the best use of resources and the most complete, thorough, and culturally sensitive outreach, response, and recovery effort possible.