

**New York City Special Needs Registry:  
Considerations and Options for Effective Implementation**

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Gray Panthers Task Force on Emergency Planning and Response for  
Special Needs Populations in New York City

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This document operates within the context of the proposed legislation Int. No. 1065-2013. It provides an important opportunity to discuss the most effective ways of reaching and protecting those with special needs, the vulnerable elderly and those with functional needs. While this document specifically references the effects of a special needs registry on older persons, the conclusions drawn herein retain applicability for a broader special needs population. Our goal is for the development of effective approaches which can be integrated into the daily fabric of New York City for the long term.

### **Background**

A special needs registry is designed and intended to provide a medium for tracking older adults and individuals with functional and access needs. Information gathered may assist responders in planning and response efforts in times of emergency. While the proposed city-wide special needs emergency registry may be intriguing, there may be reason to question its practical feasibility. The potential benefits such a registry could very likely be mitigated by the social and economic costs of implementation and maintenance on such a large scale.

New Jersey currently has a statewide special needs registry in use. However, following Hurricane Sandy, 20 out of 37 (54%) NJ deaths were 65+ years old while only 20 out of 43 (47%) NYC deaths were 65+ years old.<sup>1</sup> While it is important to remember that these data are predicated on a very small sample size, the New Jersey state registry was not seen to have any significant positive statistical impact on preventing the deaths of the aging in Hurricane Sandy. Consequently, a special needs registry such as the one proposed in New York City cannot be seen as a cure-all solution.

Contemporary research has pointed to two main criticisms of a special needs registry as proposed in NYC:

1. The opportunity costs of such a registry are simply too high. The resources devoted to registry creation, maintenance, and implementation would be much better used to promote tangible community preparedness and response measures.

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2. Even when the registry is fully implemented, it has not been seen to be successful in protecting special needs populations. Too few registrants and inadequate city follow-up capabilities have diminished efficacy.

The major critiques of the registry are founded on several philosophical and practical flaws in the framework of the system.

## Criticisms

### Participation and Maintenance:

The challenges associated with creating and maintaining an expansive and accurate special needs registry pose the most tangible threats to the efficacy of this type of legislation. Current registries across the country struggle to reach a meaningful portion of eligible special needs populations. For example, New Jersey's statewide registry of approximately 14,000 people only accounts for only about 2.5% of state residents aged 75 years or older.<sup>2</sup> It should be noted here that statistics for non-elderly special needs registrants were not included in this assessment; however, that only suggests that an even smaller percentage of the total eligible population is registered with the state. There are many reasons why these existing programs have not seen adequate participation rates:

- People of any socio-economic demographic are reluctant to self-identify as 'needy' and the premise may work to disempower registrants<sup>3</sup>
- Systemic ambiguity and lack of clarity can make it difficult for the public to engage
- Privacy and security concerns arise when collecting personal information<sup>4</sup>
- The average person is very distanced from local government institutions and is unlikely to feel comfortable interacting on this level
- People simply see it as "one more government intrusion"<sup>4</sup>

While appropriate (and potentially costly) programming may alleviate some of these concerns, there is no reason to think that New York City will have significantly more success if the registry

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is to be constructed using traditional models. Additional challenges with maintenance arise as people are unlikely to update their information when they move and deceased registrants are never removed from the database. A representative for a county registry in North Carolina reported that only one person had ever called to update his/her information.<sup>4</sup> If a registry in any city or state cannot be constantly amended to maintain accuracy, whatever information is gathered can lose credibility very quickly.

### Inefficient Response Efforts

The challenges associated with maintaining this type of special needs registry can decrease the efficiency of disaster response efforts. In situations where a registrant has either moved or died, any attempt to account for him/her following a disaster is ultimately a waste of vital resources and manpower. Additionally, many disasters occur unexpectedly and even special needs populations could be caught away from their residence and unable to return home in the following days.<sup>3</sup> This points to another limitation as the registry and subsequent relief efforts would be rendered useless.

### Next Steps:

Special needs registries across the country describe their relief capacities in very limited and vague language. Here is an example from the webpage for the Rhode Island state registry:

This system is designed to identify individuals who may require special assistance during emergencies. Enrollment in the Registry does not guarantee assistance, but allows first responders to appropriately plan for, prepare for, and respond to the needs of the community.<sup>5</sup>

This may seem unobjectionable, but it points to a fundamental problem with special needs registries. Aside from very small scale programs, existing special needs registries can only feasibly be used generally for planning and to inform the city and first responders on what to expect. Registry programming is simply not designed to provide resources and training for how to respond.

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Unfortunately, registrants often assume that participation implies that individual help is coming for them.<sup>6</sup> This is often not the case as resources are stretched thin in times of disaster and first responders might have more pressing matters to attend to. However, even when someone is able to personally check on a resident, more assistance is often expected of them than they have the capacity to deliver.<sup>6</sup> This creates a significant problem when a registrant's reliance on assumed city assistance prevents that individual from creating a personal emergency plan and preparing themselves. Again, it would likely be more prudent to equip first responders and community organizations with additional special needs intensive training and resources than to construct a list with few provisions for follow-up relief.

#### Individual vs. Community Focus:

The balance between individual and community focus constitutes a more ideological concern but remains important nonetheless. The valuation of individual need over community security is implicit in the philosophy embodied by special needs registries. While it is important to provide increased assistance to those with special needs, the city would likely have the capacity to reach more vulnerable residents through community-based special needs programming. The opportunity cost of focusing on an individual scale is seen in a compromised capacity to build overall resiliency and special needs support systems within the greater community.

### **Recommendations**

Much of the current research would seem to indicate that progressing without a special needs registry would be the most effective and cost-efficient option for New York City. Government resources could then be better invested in community resilience programs, special needs evacuation services, tools for sheltering in place, emergency generators, accessible recovery centers, etc. However, if a registry is to be effectively implemented, it would be prudent to take an alternative approach predicated on small-scale community initiatives. The traditional

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special needs registry model just doesn't seem to be feasible to manage effectively on such a large scale.

#### Community-Based Organizations (CBOs):

Introduction 1065-2013 does do well in addressing the importance of coordinating with community-based organizations in times of crisis. However, the value of CBO-government collaboration in disaster relief efforts may still be understated. While the city should be the driving force behind emergency management initiatives, government offices are often ineffective when undertaking the role of a direct link to the public. Working with local CBOs such as senior centers, church groups, and healthcare providers offers many advantages with respect to the creation of a special needs registry. CBOs offer tangible community connections that the city government simply does not have.<sup>7</sup> People with special needs value and trust these groups because they personally interact with them on a regular basis. These special needs populations would, consequently, be more likely to register and update personal information through a community group that they see in day-to-day life. CBOs would ideally take on the same responsibilities of a government task force but on a much smaller scale. Through a closer partnership with the city, CBOs would likely be able to create and maintain much more accurate and complete neighborhood special needs registries on a small scale. The information generated locally would be shared with the city government and could be utilized in relief efforts by both the city and CBOs.

Of course, community-based organizations would be hard-pressed to take on this level of additional responsibility on their own. This model would require the city to provide financial and practical resources to CBOs in order to enable and incentivize them to participate in the registry program. It would also be important to establish memorandums of understanding outlining expectations with all involved groups.<sup>7</sup> This resource commitment would take the place of the investment in creating a door-to-door governmental task force for the traditional registry model. Regardless of the cost, the program would be more successful and inclusive when conducted at the local level.

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### Increased Definition and Clarity:

Reports and evaluations of existing special needs registries have pointed to several additional recommendations to increase the transparency of the program. As previously noted, systemic ambiguity and lack of understanding among the public are two factors that can decrease the efficacy of a registry by preventing people from participating. Consequently, it is vital that any registry or similar project in NYC include clear definitions of the capabilities and limitations of the program, as well as information on who is eligible to participate.<sup>4</sup>

Existing registries have been vague in defining their exact roles in disaster management. It is vital to explicitly outline what type of support registrants can expect in order to avoid over-reliance on government assistance and ensure adequate individual preparedness.<sup>4</sup> The program's capacity to provide special needs services such as check-in calls, evacuation assistance, and door-to-door response would be defined here.

Additionally, clear classifications for who is eligible for programming may convince people who would otherwise be hesitant to self-identify as having a special need to participate. Explicit definitions here improve the general structure and efficiency of a registry as well. If the requirements for eligibility are too broad, the program will become a less effective resource in times of disaster; conversely, too stringent requirements risk exclusion.<sup>4</sup> A tiered system may be the best option here as it “allows for the registration of people with diverse needs, while prioritizing individuals with critical medical needs and allocating resources in an effective manner.”<sup>4</sup>

### Personal Preparedness:

One unfortunate consequence of implementing this type of emergency management program is the effect it can have on discouraging individual preparedness.<sup>4</sup> While government and community response efforts can be invaluable, it is always important to communicate the need for personal preparation. Many city and state emergency management offices already place a heavy emphasis on this. For example, the Rhode Island Department of Health does an excellent job providing clear, specific personal preparedness recommendations on the front page of their

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special needs registry website.<sup>5</sup> An focus on the importance of self-preparation should ideally accompany any type of citywide emergency management plan.

### **Conclusion**

This document was intended to provide a review of the critiques and recommendations found in relevant literature and contemporary case studies as they pertain to the feasibility of a special needs registry in New York City. While any effort to protect vulnerable populations in the event of a disaster deserves careful consideration, the research identified here does point to a significant number of barriers and gaps in the current special needs registry framework. Consequently, it is imperative that concerns regarding the cost-effectiveness, feasibility, and overall efficacy of the proposed special needs registry play a prominent role in any continued discourse. Many of the critiques put forth in the literature do appear to be compelling and, at the very least, suggest the need for a more critical examination of relevant legislation at the city level.

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## Resources

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