

Whole Community Emergency Management Planning in PA

Sylvia Twersky, MPH and William Flynn, MPH, Department of Public Health, Temple University; Jamie Arasz Prioli, B.Sc., Institute on Disabilities at Temple University

Introduction

There have been numerous emergency and disaster situations in recent years that have resulted in devastating outcomes for individuals with functional needs, including Hurricanes Katrina and Sandy and the 9/11 terrorist attacks on New York City. While these events were considerably different from one another, they all tested the emergency planning efforts of citizens and emergency planners with respect to evacuation, communication, shelter and medical care. Unfortunately, there is limited research about emergency planning in populations with functional needs, specifically individuals with intellectual and developmental disabilities (ID/DD).

The terrorist attacks that occurred on 9/11 triggered a major focus towards emergency preparedness planning. Surprisingly, the 2004 9/11 Commission Report did not mention the experiences of people with disabilities during the disaster, nor did it include them in the recommendations for future planning efforts (National Commission on Terrorist Attacks, 2004). Even after the integration mandates from the American Disabilities Act (ADA) of 1990, separate planning efforts towards emergency preparedness for individuals with disabilities still focused on “special needs” approaches, which resulted in segregation, separation and discrimination by inappropriately grouping individuals into one category rather than individualizing them categorically based upon their specific needs. Recent advancements in emergency preparedness have been made such as checklists, “how-to” guides, and training opportunities for emergency managers, families, healthcare facilities and other stakeholders, yet there is limited empirical support for these efforts.

Over the past few decades, there have been an increasing number of self-advocacy groups involving people with disabilities such as the “Nothing about me without me”

advocacy movement of individuals with intellectual and developmental disabilities. Prior to the ID/DD community speaking out, there were minimal opportunities to participate in areas such as learning, planning, advocacy, policymaking and governing (Arc, 2011).

In 2004, President George W. Bush implemented *Executive Order 13347: Individuals with Disabilities in Emergency Management* in order to ensure individuals with disabilities feel equally safe and secure within their communities and work environments as individuals without disabilities. Executive Order 13347 set several provisions and mandates regarding the role of the Federal Government in addressing these issues. In this document, it was ordered that the unique needs of employees and individuals with disabilities be considered. In addition, President Bush created the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities, which directed several Federal executive agencies and departments to collaborate in order to ensure emergency preparedness plans that were comprehensive and inclusive of individuals with disabilities (U.S Congress, 2004).

A recent judgment against New York City said that the city violated the rights of over 900,000 residents with disabilities by failing to accommodate their needs during emergencies (Santora and Weiser, 2013). This lawsuit was filed by two non-profit groups representing individuals with disabilities after Tropical Storm Irene in 2011. They claimed that the city violated the ADA by failing to include evacuation plans specifically for individuals with disabilities during emergencies. This lawsuit made little change to city planning efforts and during Hurricane Sandy hundreds of people with disabilities were left stranded for several days due to the absence of a citywide evacuation plan. Judge Jesse M. Furman of the Federal District Court found New York City, through “benign neglect,” violated the Americans with Disabilities Act. New York City failed to plan for individuals with disabilities in several ways, including evacuation procedures from multi-story buildings, accessible shelters, and failure to inform individuals with disabilities about the availability and location of accessible emergency services (Santora and Weiser, 2013).

The National Council on Disability provides several reasons why the engagement of individuals with disabilities in emergency planning is necessary: 1) their knowledge of

potential barriers is a major asset to plan development; 2) their personal experience in overcoming these barriers adds validity to planning efforts; and 3) the empowerment established through participation may encourage individuals with disabilities to take leadership roles and preemptive actions during emergency situations (National Council on Disability, 2010).

The present study is a component of a larger project funded by the Pennsylvania Developmental Disabilities Council and conducted by the Institute on Disabilities and the Center for Preparedness Research and Education (CPREP) at Temple University, to assess and report on current barriers and opportunities for the participation of people with disabilities and their families in emergency planning at the local, county and state levels. A second component of the project is to develop training for individuals with disabilities, family members and emergency planners to further facilitate inclusive emergency management in Pennsylvania.

With the intent to enhance the direct involvement of people with disabilities in emergency planning discussions at all levels across the Commonwealth, we undertook two research projects: 1) semi-structured key informant interviews with emergency management professionals at the state, regional and local levels and 2) two consumer surveys, including a survey of people with intellectual and developmental disabilities and a survey of family members and caregivers of people with intellectual and developmental disabilities. The information we collected through the interviews and surveys informed the development of the training program for emergency planners and individuals with disabilities and their families.

Key Informant Interviews

Methods

We conducted interviews with 12 key informants from local emergency management agencies, regional emergency management structures, and state organizations involved in emergency management to identify perceived barriers and facilitating factors, as well as direct experience, when including individuals with disabilities in the emergency planning process. An interview script and coding schema were developed through a

review of existing literature, and reviewed by the project advisory committee composed of local, regional and state-level emergency management representatives as well as individuals from the disability community. The coding schema and interview script were designed to identify inclusion of individuals with disabilities in the various emergency management planning and training activities performed by local agencies, positive and negative experiences based on previous emergency situations involving individuals with disabilities, methods of outreach to and accommodation of the disability community, and emergency management professionals' perception of individuals with disabilities and the emergency management process. Findings from the interviews were used in conjunction with results from an electronic survey of individuals with disabilities and their family members to develop training curricula on emergency planning and inclusion for emergency managers and individuals with disabilities. Furthermore, the findings from this study will inform policy recommendations on inclusive emergency planning.

Procedures

All study procedures were approved by the Institutional Review Board at Temple University. The project manager, William Flynn, conducted phone interviews with key informants from local, regional, and state emergency management agencies in Pennsylvania. The 12 key informants were chosen through a snowball sampling method, where we used the advisory committee to identify potential contacts and then asked the contacts to either participate or suggest someone else to participate. Potential interview participants were contacted if they were an employee or volunteer at a statewide, regional or county government or non-profit organization in Pennsylvania and their employer has a role or responsibilities pertaining to emergency management planning. Direct email and phone calls were used to contact potential key informants in January and February 2014. A consent form was then sent to individuals who agreed to participate. An interview guide was developed based on a review of existing literature and feedback from the community advisory board composed of local, regional and state-level emergency management representatives and individuals from the disability community. The key informant phone interviews took place between January 2014 and June 2014. Study participants had the option to refuse to participate or withdraw from the study at any time without penalty. The interviews were recorded and transcribed.

Data Analysis

After transcription, the interviews were coded using a schema developed through a review of the literature on functional needs and emergency management, as well as identified best practices for inclusion and outreach. The coding schema was designed to identify various themes including accessibility and inclusiveness of outreach communication, accessibility and inclusiveness of planning and training events, emergency managers' perceptions of including people with disabilities in the planning process, and barriers and facilitators to including people with disabilities. Three coders tested the codes using one transcript, and revised the schema based on inter-coder reliability. Discussion of areas of difference in coding among the three coders was used to develop the final coding for all key informant interviews. A content analysis was performed on the finalized coded transcripts.

Coding Interview Transcripts

A coding schema was developed by the research team in order to identify and categorize responses in the interview transcripts. The codes "barrier" and "facilitator" were used when subjects referred to factors that either prohibited or facilitated the completion of an intended action. For example, if an individual mentioned that a certain resource or activity was beneficial to their organization's goals around emergency management, the code "facilitator" was used.

The coding system was designed to identify when subjects referenced activities performed during the response and recovery phases of emergency management such as evacuation and recovery activities. Codes were also included to identify when subjects referred to emergency management planning activities and emergency preparedness training activities. Specific codes were included to address subjects' references to "train the trainer" activities, or the direct provision of training.

Next, multiple outreach events were identified by outreach target, such as outreach to the general community, service agencies, family members/caregivers, and people with access and functional needs. There were codes for use of various communication methods, including telephone, email list, social media, word of mouth, or integrated messaging system (communication across multiple platforms).

Codes for the emergency management professionals' positive and/or negative perceptions of programs or organizations were included, as well as for their perceptions of the capabilities or needs of people with disabilities. There was also an identifier for the referencing of laws and regulations that addressed issues of inclusive emergency planning for people with disabilities, and a separate identifier for referencing organizational, local, state or federal policies.

There was a code for the referencing of government organizations, defined by federally funded emergency management organizations/agencies such as FEMA, Red Cross, etc. A code for service organizations, defined as local organizations/agencies that provide direct emergency related services to individuals such as fire departments, EMS, etc., was included. Professional networks were identified when a professional contact at government or community based service providers was referenced. A code was available for citizen advocates within the community.

Human resources was a code used when subjects referred to staff and support personnel available to address inclusive planning, training and outreach. A "knowledge level" code was used whenever subjects expressed certainty or uncertainty regarding services and appropriate practices. Any mention of a community experience with a specific disaster was recorded through a code.

Results

LOCAL KEY INFORMANTS

Demographics

Five key informant interviews were conducted with emergency management professionals from two local Emergency Management Agencies, as well as local Department of Human Services, Office of Behavioral Health, and Department of Emergency Services. Two of the agencies are located in urban counties and three in rural counties as defined by the U.S. Census Bureau. Participants consisted of two males and three females. The length of time the five participants held their current job

position was 2, 14, 18, 23 and 24 years. Three participants had supervisory positions, and two held roles as coordinators. Some of the roles and responsibilities of various agencies included creating/reviewing emergency plans for nursing homes, conducting outreach events in schools, churches, senior centers and fairs, providing mental health services after emergencies, direct training and emergency response.

Outreach and Communication

The most common barrier experienced to including individuals with disabilities in emergency planning was difficulty in identifying individuals with disabilities within the community:

We spend a lot of time talking about the whole community, making sure that everyone in all aspects, all the audiences in your community, are being included in your plan. But what still throws me now is how to include them [individuals with disabilities] in the planning process. I know I might have included them in my plan, but they aren't in the planning process. Those are different. Including them in the planning process means first of all, figuring out who they are, and then figuring out what they need so that we can make sure that it's addressed.

This sentiment was echoed in the conversation with other emergency managers. Frequently emergency managers had included provisions for individuals with disabilities, but had not taken steps to include individuals with disabilities in the process of writing the plans. When addressing community outreach, many of the barriers resulted from a lack of knowledge about the disability community, specifically what their needs were and how to reach them. Three of the five key informants acknowledged that their own knowledge level regarding the needs of the disability community and outreach methods were barriers to involving people with disabilities in emergency planning. One of the key informants expressed concerns about this issue:

I'm actually concerned because we're talking about inclusiveness and people with disabilities and special needs. We have a lot of concerns that we're reaching all of our appropriate audiences, all of the people that we're working to protect. Are we able to know where they are?

Interview participants also explained their perception that the disability community is reluctant to self-identify. In the context of registries, one informant commented "We also have a difficulty in rural America here with people seeking out that information and being willing to step up and ask somebody." There seemed to be the belief that identifying partners in the disability community would be difficult because of the reluctance of individuals with disabilities to be categorized as such.

Outreach through social media outlets was utilized by four of the participants. There was some disagreement as to the utility of social media. Two informants described Facebook as problematic for communication and two as a facilitator for communication. The main barrier reported on outreach through Facebook was the fact that trying to perform direct communication to a certain population was inefficient. Problems noted included the fact that messages/posts had to be generalized to cater to all individuals, and also that the social media platforms have so much additional incoming content, possibly distracting attention from emergency related posts. However, one of the emergency management professionals found multiple social media platforms as a definite facilitator for outreach, specifically Facebook and Twitter. They post links to various resources, emergency alerts, agency updates and weather alerts. Another key informant reported having good conversations with other individuals and organizations on their Facebook page. Three out of the five organizations reported having an integrated messaging system in place, and one specifically mentioned Everbridge as their favorite messaging system. Three out of the five organizations reported routine use of email to members of the general community on a listserv.

Training and Knowledge Level

One identified barrier was a lack of training about the particular needs of individuals with different disabilities in the event of an emergency:

I think that spotlighting and reminding people that not everybody is gonna be able to pick up their "grab and go" bag and run out to a shelter if something happens, not everybody is prepared for whatever situation. We need to be alert and knowledgeable. I think maybe a little bit of training on what to do with deaf people or those with intellectual disabilities.

However, this did not necessarily translate in the informant's mind into including these different individuals in the planning process so that they could self-identify their needs in

an emergency. Instead it was seen as a more didactic need for planners and responders.

One of the key informants gave a perspective on future directions towards including individuals with disabilities in the emergency planning process:

The first step is raising the awareness level not only myself but my staff and management teams. Raising awareness in the small inner circle so that once we are comfortable with the understanding of what the terms, definitions and quite frankly what it looks like, then start to move out into the other groups that I deal with. The very, very first thing is going to be education, which is a part of awareness.

A lack of personnel was identified as a barrier to conducting trainings specifically targeting or including individuals with disabilities in two ways: 1) a shortage of hands-on help for conducting training activities and 2) lack knowledge and resources needed to create training materials. In the process of working with the LINK program (Aging and Disability Resource Center), one participant identified and conducted a training called “Feeling Safe, Being Safe”, created specifically for individuals with disabilities and their caregivers by the California Department of Developmental Services. All materials were available on the web which made it easy to find and duplicate. The most helpful resources identified by emergency professionals were online trainings and training manuals. These helped individuals to become more knowledgeable about overall preparedness, people with disabilities and additional resources. Another resource mentioned was “grab and go” bags provided by the Area Agencies on Aging (AAA). The AAA partnered with the Pennsylvania Department of Human Services and did an outreach event on preparedness at various senior centers. Residents were given a “grab and go” bag, and trained on how to be prepared for an evacuation. The majority of trainings identified all focused on teaching individuals with disabilities to become more prepared in the event of an emergency. One of the key informants spoke about how helpful it is when their organization is able to create partnerships with nursing homes and daycare centers in order to help create emergency plans that meet the specific needs of clients.

Considering that the facility primarily knows the special needs of their clients, we rely on them to make sure that they know what the needs are that we can assist them with. That's our hope, to reach in and have partnerships to help them understand how we can help them be prepared. We can't do it for them and they can't do it without us.

Similar types of partnerships and collaborations were made by another emergency management agency, which worked to pre-identify facilities that had people with disabilities.

We have to pre-identify so we know that we would be looking at a group of people with special needs who might need additional assistance. We have previously identified most of those locations and do encourage working with them, nursing homes etc., and similar environments to make sure that their emergency operations plans are in place. Each of those agencies needs to be able to facilitate their own response, and it is our responsibility to support that response.

One of the emergency management professionals was describing a recent situation in which they went out to review an emergency plan of a nursing home located near a power plant, and encountered a surprising situation: "One of the plans that reviewed was for a nursing home, where their plan said, 'for radiologic emergencies, their staff and residents would get on the floor and cover their heads.' So we're very concerned that appropriate responses have been listed as well as evacuations plans."

Professional Networks

Beneficial partnerships were reported with governmental entities as well as service organizations. Positive outcomes from these partnerships included assistance in developing trainings and procuring meeting and event spaces. Key informants reported government partnerships with entities such as the Bureau of Public Health Preparedness, Pennsylvania Emergency Management Agency (PEMA), Pennsylvania Department of Transportation (PennDOT), and law enforcement agencies. One key informant partnered with the Bureau of Public Health Preparedness to coordinate the Safe Behavioral Health Response Consortium.

Community-based and service organizations, including the American Red Cross, Salvation Army, Area Agencies on Aging (AAA), hard of hearing/deaf task force, Board of Adjustment (BOAD), regional task forces, Rails to Trails, Christ in Action, the LINK, Medical Reserve Corps, Safe Behavioral Response Consortium, local school districts, emergency response teams, Chambers of Commerce and environmental groups were also identified as helpful collaborators.

Personal Experience

Barriers during emergency response were experienced by three out of the five agencies. During Hurricane Ivan (2004) there was a lack of accommodations for individuals with disabilities. Flooding became severe enough that trucks drove around blasting foghorns to signal the need for evacuation. However a woman with a hearing impairment was napping with her 3-year old grandson and did not hear the horns. Luckily she eventually awoke and realized that her inability to hear the foghorns might cost her grandson his life.

A second situation occurred during Tropical Storm Lee (2011), when a woman called the agency to report losing power and the family needed a generator for her husband who required an airbed for medical reasons. The agency could not get her a generator, and they were left to recommend that the individual either sleep on the deflated airbed or go to the hospital. The interviewee expressed frustration that the couple didn't have a generator at their home prior to the emergency, as power outage is a frequent problem in the area.

The last situation reported was during a flood in September of 2011 when trying to evacuate a boy with autism. The emergency professional was contacted in order to assist in evacuating the boy, but was not informed he had a disability. As a result, they had to "scramble" in order to safely perform the evacuation. The informant expressed how much smoother the process could have been if they had prior knowledge of the boy's needs. In these three examples, one involved an acknowledgement of the agency's responsibility to provide accessible communication to meet the needs of all individuals in the community. The other two instances were more focused on the lack of preparation on the part of the individuals with the disability. In all cases the need for

emergency managers to be able to know the access and functional needs of individuals in their community and understand how to accommodate those needs was recognized.

Regional Key Informants

Demographics

Three key informants from regional level emergency management organizations in Pennsylvania participated in one hour interviews. Geographically, one participant was from the western region of PA (representing 25 counties in the Commonwealth), one from the central region (representing 21 counties), and one from the southeastern region (representing 5 counties). One participant worked in one of Pennsylvania's emergency management regional task forces and two participants were from regional Red Cross chapters. Time in current position for all participants was between one and three years; however all had longer careers in emergency management and public health preparedness.

Outreach and Communication

The three regional key informants have job requirements that involve different levels of community and service agency outreach. The two participants reported that their organizations used both Facebook and Twitter, but neither participant was directly involved in the social media communications. Both Red Cross informants identified public events like exhibit tables or fairs as additional methods of general community outreach. One of these participants preferred events where she could provide more in-depth presentations to an audience, while the other saw events like county fairs as a useful opportunity to meet people from the region in person.

Email (or email via listserv) was identified as a common outreach and communication method by all three regional level key informants. One described using a listserv of over 1,000 agencies that serve people with disabilities in their region to pass along guidance from state and federal level organizations. This participant also utilized service agencies to disseminate information about upcoming speakers related to emergency management and people with access and functional needs. The informant mentioned that their communications with the general public and service organizations for people with disabilities contained language about requesting reasonable accommodations, but

was quick to point out that planning for such accommodations had to start before the emails were sent out: “We also work to make sure that our conferences are held in places that are accommodating for people with physical disabilities. For example, making sure there are ramps; making sure the restrooms are located close to the conference rooms”. This participant’s comments highlighted the importance of advance planning for accommodations in order to meet the needs of the disability community.

Two out of three regional key informants emphasized that they didn’t target specific organizations or types of disabilities, but talked to their service agency partners to learn more about the community’s concerns. Typically, they developed their outreach network by branching out through referrals from existing contacts. In general, regional informants were more likely to communicate with and include service agencies than individuals with disabilities, themselves. This may be because regional organizations have less direct response functions and more professional training and planning functions, so they do not see outreach as part of their role. This also reflects the lack of direct inclusion of individuals with disabilities in the planning process for emergency management.

Training and Knowledge Level

One out of the three regional-level key informants was directly involved in training within their community. This participant discussed an eight-hour workshop their organization had developed for agencies providing in-home care that focused on the creation of emergency and continuity of care plans for their clients.

More and more of our population, probably nationwide, but we know particularly in Pennsylvania, you know, are able to stay at home with significant needs that are being provided for them by family or house caregivers in their home. We give them a great deal of independence that can also make them very vulnerable in the time of a disaster or evacuation or fire.

The advisory committee that oversaw the development of this training included a person with a disability.

The key informants at the regional level all reported that they frequently were planners for or participants in table top and functional exercises. One of the regional organizations held frequent refresher trainings and their own annual small scale, shelter-focused functional exercise. These small scale exercises did not involve external service agency partners or community members, but incorporated role-play scenarios addressing accommodations for people with disabilities.

One participant described an evacuation exercise they had been conducted with an urban nursing home facility. Approximately 60 out of 100 facility residents participated in this exercise. On the subject of the resource commitment from the facility, the informant remarked, "...the nursing home doubled its staff for that day, and so they were able to provide continuing care for those who chose not to participate". This type of exercise provides exposure for responders to the needs of individuals with disabilities at the same time informing those individuals and their caregivers about the importance of emergency planning .

Another participant discussed inclusive planning and training activities in the context of a federally-required nuclear power plant exercise. As part of this exercise, which was planned by a group that included the informant, the participating county-level organizations were responsible for canvassing a 10-mile radius around the power plant. As a result of this training activity, the county emergency management organizations got a sense of how many individuals might need transportation assistance in an evacuation scenario.

Knowledge level among the regional participants was a significant facilitator. All three had spent their professional time considering the big picture implications and practical details of including people with disabilities in emergency plans. In two cases they had directly included people with disabilities in the planning process through participation in exercises.

At the same time, training and knowledge level were two barriers that were cited throughout the interviews at the regional level: "I don't think most people understand the legal obligation that anyone who has – opens a shelter has. The recent court decision

in New York made it very clear that there was not – not only the services provided, but they also spoke to the fact that the community had not been involved in the planning process.” This quote shows recognition that engaging service agencies is not a substitute for direct involvement of people with disabilities, and the idea that legal requirements for inclusion and accommodation play a role in decisions about the emergency planning process.

Professional Network

Regarding representation and inclusion of people with disabilities in planning activities, one regional key informant remarked: “I’m very proud that we’ve had consistent participation of people, representing blind people and deaf people coming to our meetings. Obviously that doesn’t incorporate a large majority of the functional needs”. This informant’s concern, that despite efforts to outreach to “the whole community” and to service organizations serving people with disabilities, representation in planning activities was not truly reflective of the diverse needs of the disability community, was shared by all three participants at the regional level.

Pennsylvania state-level government organizations cited as collaborators at the regional level included the Department of Public Welfare (now the Department of Human Services), Department of Health, and PEMA. Each regional level participant had strong relationships with the emergency management agency (EMA) for the counties within their region. Service agencies cited by regional key informants as exemplary partners and resources included Philadelphia Coordinated Health Care, Allegheny County Disabilities Connection, The Alzheimer’s Association, Germantown Deaf Ministries Fellowship, Deaf Hearing Communications Center, and Associated Services for the Blind. These organizations reflect the individual participants that were mentioned as involved in planning or exercise activities at the regional level, including older individuals in nursing homes and individuals with hearing and vision impairments.

Relationships with and outreach to service agencies for people with disabilities were also seen to facilitate better inclusion of people with disabilities. Because of the client networks these organizations have, they are often in an ideal position to provide important information directly to people with disabilities. While the importance of such

networks should not be understated, one key informant also identified the growing importance of reaching out and working with people with disabilities directly:

I can tell you that it is very much at the forefront of our minds as we do our planning, that our population that we serve is increasingly at home with significant disabilities and health needs, and we're very aware of that. And we are working hard to make sure that we know what those needs might be, and forming partnerships, so that when we do have an emergency we know who to call to provide the very best support in our area that we can.

Financial concerns were also identified as barriers. The question of who would pay for the solution if and when a problem was identified often inhibited implementation. In other cases, participants felt that limited human resources – related to financial issues – prevented some training and education programs from being successfully implemented or scaled.

Personal Experience

Relationships between informants and people with disabilities often played a role in the regional level participants' awareness of the topic. One participant discussed an experience during Hurricane Ivan in 2004 that brought home the need for planning and training specifically for individuals with disabilities:

It was just, a very trying experience to see people who were comfortable in their homes one second, and literally a minute later, there is just a wash of water, and they were being pulled out and put onto a school bus. I don't know how long it's been since you were on a school bus, but it's not very comfortable. So we had people in wheelchairs with all kinds of limitations, and that was just a safety issue at that point. I was there at the shelter when they dropped them off, and it was a very dramatic and challenging circumstance, and we did everything we could to make everyone as comfortable as possible in the emergency situation. We started moving quickly to get these kinds of equipment, wheelchairs, and getting services out there so that we could make sure

everyone was okay. So yeah, it happened, it was unexpected, and everyone does the best that we can do.

Encountering people with disabilities during emergency response in scenarios like this were seen by this informant as, on a personal level, increasing awareness of the importance of including people with disabilities in planning.

Another regional participant expressed concern with the knowledge level of emergency management professionals at the local levels:

... we got a call at the state EOC [Emergency Operations Center] from the fire chief who was complaining that a husband was changing his wife's colostomy bag in the shelter and he really thought she should be in a hospital for that. And I think that's a great example of the lack of understanding at many levels, of just what is meant by access and functional needs that they are to be accommodated in a general population shelter.

Close personal and professional relationships with people with disabilities also seemed to inform participants' perception of people with disabilities and inclusive planning. One participant who expressed concern about the knowledge level of local emergency managers also discussed a family member with a hearing impairment. The participant said that they used this family member as a point of reference when engaging in planning activities.

State Key Informants

Demographics

Four emergency management professionals at Pennsylvania state level agencies were interviewed as key informants. Two of these participants were from the Pennsylvania Emergency Management Agency, one from the Department of Public Welfare (DPW, now the Department of Human Services [DHS]), and one from the Governor's Cabinet and Advisory Committee for People with Disabilities. Time in position ranged from one to three years.

Outreach and Communication

The four participants did not have significant job responsibilities related to outreach to the general public. Two had roles where they outreached to a wide variety of human service organizations, including organizations that served people with disabilities, but the informants did not specifically target those organizations. Both participants who conducted outreach as part of their position reported that they communicated regularly with county level emergency managers and service agencies by email.

The state level key informants were not directly involved in community outreach. The three informants at PEMA and DHS received their guidance from the federal level – or other states - and provided resources and guidance to county and local emergency management professionals across the states. In at least two cases, the participant had developed professional relationships with organizations serving individuals with disabilities.

Training and Knowledge Level

Only one participant at the state level had professional responsibilities directly related to training. This participant oversaw the “train the trainer” program for a statewide network of emergency response volunteers. This informant said that part of the training process covered including people with disabilities in volunteer response teams. The informant had been encouraging local team leaders and instructors to include people with disabilities on their teams and told recruiters that “...if you’re struggling for people, please don’t discount anyone because of [they have a disability].”

All four informants had participated in, or had been part of the planning process for large scale functional exercises. Three participants discussed a sheltering exercise at Shippensburg University. Visiting the site of a potential state-managed shelter in an exercise context demonstrated for participants the importance of testing plans to make sure they are fully accessible. “In terms of people with disabilities we kind of all walked in there from the ride down and one of the first things I realized was there was no convenient men’s restroom accessible.” Eventually an accessible men’s room was found, but the interviewee identified that the lack of convenience and difficulty finding

the accessible restroom's location could prove very uncomfortable in a shelter environment operating for several thousand people.

Knowledge level about the legal and regulatory requirements for accommodation and inclusion of people with disabilities was identified as a facilitator for the state level interviewees. Two informants referenced recent lawsuits in New York and California and saw their organizations making an effort to address the areas identified in those suits. One discussed using data from Louisiana following Hurricane Katrina to learn more about evacuation of people who rely on public transportation and who have access and functional needs.

Professional Network

One key informant highlighted the challenges posed by working with stakeholders from representing people with disabilities who have varied access and functional needs:

...we want everybody at the table to bring things together. But, even within your organizations that are advocates for the access and functional needs, we have found that there is sometimes not a clear picture. We have one organization saying that they want this and they need this. The other organization, 'Well, that doesn't make any sense to us. We want this.'

The perceived complexity of addressing the varied needs of people with disabilities and people with access and functional needs were discussed in three of the interviews.

The participants from all three organizations had worked with each other's organizations at some point. Additional state level organizations that were considered collaborators included The Office of Mental Health and Substance Abuse Services (OMHSAS), Department of Transportation, and Department of Health, and the Pennsylvania State Association of Township Supervisors. All four key informants at the state level mentioned changes and restructuring taking place across agencies involved in emergency operations. The Department of Human Services (then the Department of Public Welfare) had recently been tasked with operating state-managed shelters.

One participant mentioned using resources from other State's emergency management agencies, specifically the Virginia Division of Emergency Management's sheltering plans. Networking and incorporating best practices from around the country was viewed as an important component of improving existing plans. Several participants also referenced frequent contact with the FEMA Region III office (the region includes Pennsylvania, Maryland, Delaware, Virginia, West Virginia, and the District of Columbia). This office has an Accessibility Coordinator who was cited as a great resource. Other federal agencies mentioned by participants included the Centers for Disease Control and Prevention (CDC) and the US Department of Health and Human Services (HHS).

An informant also identified varying engagement with the issue of inclusive emergency planning under different administrations and agency leadership. This informant made a point to clarify that it was not specifically an issue of Republican or Democratic leadership, but rather that the personality of the leadership at the agency and state government level had a great impact on what could get done and how willing agencies were to collaborate with one another.

State level emergency management professionals have to consider the entire demography of Pennsylvania – rural and urban. In developing the state-managed shelter plans, Pennsylvania's system of higher education was chosen as a partner because of its distribution across the state and cache of resources. In the words of one participant "...the point being is that this is something that's designed to be fairly standardized, that can meet its – that can be self-sufficient for a limited period of time." In selecting these locations, they also incorporated into their planning the need to consider the spectrum of challenges that people with a wide variety access and functional needs might encounter in a variety of emergencies and disasters.

Personal Experience

Three participants discussed the opening of a large scale shelter during Hurricane Sandy as part of an Emergency Management Assistance Compact (EMAC) request from New Jersey Governor Chris Christie. Although this shelter was not used to its full

capacity (the maximum occupancy was set for 25,000), the experience revealed gaps in shelter planning for individuals with disabilities.

Identifying these gaps informed planning for future state-managed shelters and sheltering exercises. One participant described some recent challenges encountered during an ice storm when the state opened and managed a shelter at West Chester University in the southeast region. “One of the things that we were seeing was that there was approximately 20 to 30 percent of the people coming into the state-managed shelter – and the other shelters, for that matter – were people with some type of special needs.” This demonstrated to the informant that, despite some of the lessons learned from their previous disaster experience and training, they needed to account for a greater number of individuals with access and functional needs and a greater variety of those needs.

Discussion

Across the three levels of interviews we conducted, some common themes emerged. Personal relationships and relationships with service agencies that serve individuals with disabilities was seen as an important factor in facilitating conversation, outreach, and inclusion across all three levels of planning in Pennsylvania. Across these three levels, key informants felt that the issue of inclusive emergency planning was receiving more attention than it had in the past. This additional attention was attributed to a variety of factors including the recent class action suit in New York City (Brooklyn Center for Independence of the Disabled vs. City of New York), and awareness of the number of people with disabilities living in the community across PA. Three important facilitating factors that enabled organizations to complete intended actions mentioned by key informants included partnerships with other organizations, resources and comprehensive emergency plans that were created and practiced prior to actual emergencies. Through overlapping circles, Figure 1 illustrates the inter-relationship among the facilitating factors of familiarity with/knowledge of the needs of individuals with disabilities; outreach to the disability community, and partnerships with self-advocates and disability organizations.

The large diversity of disability-related accommodations was seen to be a barrier at multiple levels. Emergency managers are given the responsibility to address the needs of those with sensory impairments, mobility disabilities, intellectual disabilities, non-English speakers, and

people with other access and functional needs during emergencies. At the same time, this task requires personnel and financial resources that many organizations struggle to find.

Knowledge level and education were the most frequently cited barriers across all three levels. Knowledge level regarding inclusion of people with disabilities in emergency planning across Pennsylvania was described as uneven, and there were not seen to be enough educational opportunities for emergency managers to address this. Informants at state and regional levels who had less opportunity for direct community outreach perceived limited utility and/or responsibility for outreach and inclusion. In these cases they saw their role as encouraging others to undertake these activities at the local level.

One set of barriers identified were logistic issues around accommodations and durable medical equipment. Even where the state had provisioned durable medical equipment for shelters or other emergency uses, moving equipment from caches to a site where it was needed was identified as a potential challenge. One key informant remarked that plans for transportation and management of such equipment needed to be solidified.

Consumer Surveys

Methods

We developed and disseminated two versions of an online consumer survey about the involvement of people with intellectual and developmental disabilities in emergency management. One survey was designed for individuals with intellectual and developmental disabilities (ID/DD) and one for the family members or caregivers of people with ID/DD. Both versions of the survey were developed using feedback from the project advisory committee and were tested by a convenience sample of volunteers from the target populations. The survey questions covered topic areas including basic demographic information, past experience in emergencies and disaster, engagement in community emergency planning activities, and personal emergency plans. Respondents had to be 18 years old or older and residents of Pennsylvania. The survey was disseminated through six different organizations serving people with intellectual and developmental disabilities and their family members or caregivers. The survey was open for one month. There were 130 valid responses total for both versions of the survey (103 respondents were family members or caregivers and 27 respondents were

people with ID/DD). Findings from the consumer survey were used in conjunction with interviews with emergency management professionals in Pennsylvania to develop training curricula for emergency managers and individuals with disabilities. Furthermore, the findings from this study will inform policy recommendations regarding including individuals with disabilities in the emergency planning process.

Procedures

All study procedures and tools were approved by the Institutional Review Board at Temple University. Two versions of the survey were developed. The content area in both versions of the survey was developed based on identified best practices in the literature, white papers around engagement in emergency planning for functional needs groups, and the expert advice of emergency managers and advocates for the ID/DD community. The contents (questions and responses) of both versions of the survey were analyzed using reading level algorithms (Flesch–Kincaid, SMOG) and adjusted to improve readability. The guidelines for 508 compliance in online surveys were used to ensure accessibility for individuals with disabilities. The project advisory committee, which includes emergency management professionals and individuals with disabilities and family members, reviewed the content and format of both versions of the survey and their feedback was incorporated. The consumer survey was then pilot tested with a convenience sample of two individuals with access and functional needs in order to assess appropriateness of questions and format. The family member caregiver survey was pilot tested with a convenience sample of two family members or caregivers. The feedback from the end-user pilot testing drove changes to survey design and wording.

Information collected from survey questions about basic demographic information included age, sex, race and ethnicity. The survey asked participants about their past experience and attendance at emergency planning meetings, emergency preparedness trainings, and emergency management exercises. If they indicated that they had attended one of the emergency planning activities above they were directed to questions to describe the participation experience. Questions about past experience with emergency and disasters addressed the types of disasters by which the participants had been affected (hurricanes, earthquakes, hazmat event, etc.) and what

effect those disasters had on the participant (including whether they left home to go to a safe location, went to a shelter, spent more than a day without power, etc.). Both versions of the survey had a branching design. Questions about current emergency plans branched based on the living arrangement of the person with an ID/DD (whether they lived by themselves, with family, or a community group home or other institution). For example, individuals with an ID/DD who lived in a community group home or other institution were asked if anyone had spoken to them about the facility emergency plan, while people who lived by themselves or with a family or roommates were asked whether they had a written emergency plan. Participants who responded to the version of the survey for individuals with ID/DD were asked about their own emergency plans, and those who responded to the version of the survey for family members and caregivers were asked about the plans for the person with the intellectual or developmental disability. This survey was developed using Survey Monkey which is a 508 compliant platform.

Survey participants were recruited through the email lists of six organizations serving people with intellectual and developmental disabilities and their family members or caregivers. These lists were sent an email containing a link to the surveys. A second email reminder the survey was sent two weeks later to alert anyone who had not already participated. A link to the survey was also posted on the Facebook page of Temple University's Institute on Disabilities for the period the survey was open.

Results

A descriptive statistical analysis was performed on the survey results. There were 130 valid responses total for both versions of the survey (103 respondents were family members or caregivers and 27 respondents were people with ID/DD).

Family Members and Caregivers

Demographics

Among family members and caregivers for people with an ID/DD, 5.8% (n=6) were ages 18 - 29, 34% (35) were 30 - 49, 52.4% (54) 50 - 60, and 7.8% (8) were 65 and up.

86.4% (89) of family caregiver participants were female, and 13.3% (14) were male. The majority (66%) had completed a bachelor's degree or higher (Figure 2).

The survey asked about the type of disability that their family member lived with. Multiple answers were allowed so that individuals with multiple disabilities could be accounted for. Therefore, the combined percentage of individuals in the sample with each disability will be greater than 100%. The disability that affect the greatest number of individuals, 72.8% (75), was that the person in their life with an ID/DD had difficulty understanding and /or remembering information. Over half the respondents, 59.2% (61), indicated that the individual had problems speaking or being understood and 58.3% (60) took medication. 40.8% (42) had mobility issues, 35% (36) reported that they were sensitive to light and / or sound, 12.6% (13) were blind or had low vision, 9.7% (10) had special medical needs such as breathing issues requiring oxygen tanks, 8.7% (9) were deaf or hard of hearing, and 1 person reported that English was the person's second language. 80.6% (83) reported that the person in their life with an ID/DD had 2 or more "functional needs" (Figure 3). Most (72.8%) reported that the person with an intellectual or developmental disability lived with them (Figure 4).

Disaster Experience

41.8% of family member / caregiver participants had been affected by 2 or more types of disasters. Experience with Snowstorms / Ice Storms was the most frequently reported disaster that affected participants, followed by Hurricanes and Floods (Figure IV). As a result of any disaster in the past 2 years, 43.7% had spent more than 1 hour without power, 22.3% (23) spent more than 12 hours trapped in their home, 9.7% (10) left home to go to a safer location, 7.8% (8) spent more than 1 week without power, and 7.8% (8) had contact with emergency responders. Loss of power and the need to shelter in place were the two most common disaster outcomes that the respondents needed to prepare for. No one reported using an emergency shelter.

Among the 91 participants who responded regarding experience using a personal emergency plan during a disaster: 32% reported that they did not have a plan, 29.1% reported that their plan worked "somewhat", and 27.2% reported that their plan was effective.

47.6% of 101 who responded to the question felt that the person with intellectual or developmental disabilities will have the support they need in the event of an emergency. The majority however did not feel that adequate support was available, 26.2%, or were unaware whether it was available or not (24.3%). This means that the existence of a personal plan for the caregiver does not mean that a support structure is in place for the individual with ID/DD and this is definitely an area that requires improvement. Analysis of whether support was different based on living arrangements of the person with ID/DD showed that among respondents who lived with the person with ID/DD (n=73), 57.5% said they would not have the support they needed or that they didn't know. For participants who answered that the person with ID/DD lived in a community group home (12), 75% (9) said they would have the support they needed. This further indicates that individuals with ID/DD living in the community do not have the necessary support structure in place in the event of an emergency or disaster.

Emergency Planning Participation

A very small number of family members and caregivers have participated in the emergency planning process. 14.6% (15) reported that they had been to an emergency planning meeting and 16.5% (17) reported that they had been to an emergency management exercise. A larger number have participated in some type of informational training. 24.3% (25) had been to an emergency preparedness training. 13 of 15 who had attended an emergency planning meetings felt that the information presented at the meeting was easy to understand. 4 of 14 responded that they were not listened to by emergency planners or were not sure. A higher percentage of those with "some college" or higher had attended emergency planning events (planning meetings, exercises, and preparedness trainings). A higher percentage of participants who had experienced flooding attended emergency planning events than those who had experienced disasters other than flooding. Family members and caregivers of people who lived in a community group home were more likely to report having participated in emergency management exercises.

Looking at the question of whether participation in planning is more likely for individuals who are personally prepared, 13 of 14 (92.9%) who had attended an emergency

planning meeting and answered regarding the effectiveness of their emergency plan indicated that they had a written plan that worked at least “somewhat”. This was a greater proportion who had a plan than those who did not attend an emergency planning meeting. The proportion of those with a written plan was also higher among those who attended an emergency management exercise (14 of 16), and among those who attended a preparedness training (19 of 23). It is clear that awareness of the importance of personal emergency management planning either precedes or comes from participation in the planning process, and therefore personal preparedness training may be an entree for involvement in community wide planning. Among participants who indicated that the person with ID/DD would have the support they needed in an emergency, 58.3% had attended an emergency management exercise, and 60.4% had attended emergency preparedness trainings. Considering the small number of participants that were active in the planning process who had received emergency education, this indicates a strong relationship between these activities and feeling that their family member with ID/DD would be supported in an emergency.

An important aspect of understanding participation in the emergency planning process is family members’ interest. 57 out of 102 who responded said they would be interested in attending emergency planning meetings in the future. 44 out of 100 were interested in emergency management exercises, and 61 out of 101 were interested in participating in emergency preparedness trainings. Thus, about half of respondents have an interest in the planning process and slightly over half are interested in receiving training.

Individuals with ID/DD

Demographics

Among the survey participants with intellectual or developmental disabilities 22.2% (6) were between 18- 29 years old, 37% (10) were 30 - 49, 37% (10) were 50 - 64, and 3.7% (1) were over 65. Participants were 67% (18) female and 33% (9) male. Looking at the type of community participation respondents were engaged with on a daily basis, 51.9% (14) reported that their weekday activities included working for pay, 48.5% (13) stayed home, 18.5% (5) volunteered, and 11.1% (3) went to school. 59% reported two or more access or functional needs. The most common functional needs reported were

taking medication (48%) and mobility issues (44%). Problems understanding information and sensitivity to light and sounds were also commonly reported (Figure 5 and 6). This indicates a need for emergency managers to think critically not only about preparedness activities but also messaging that will be effective for people with disabilities.

Disaster Experience

Among the participants with ID/DD, 37% (10) reported that they had experienced two or more disasters. Given Pennsylvania's location, and consistent with the family member and caregiver survey results, it is not surprising that snowstorms and ice storms were the most frequently experienced type of emergency or disaster (Figure 7).

In response to the question about the effect of past disasters, 33.3% (9) had contact with emergency responders, 25.9% (7) reported they had left their home to go to a safer location, 22.2% (6) spent 12 hours or more trapped in their home and 14.8% (4) spent more than one week without electricity. One person went to an emergency shelter. From this information it appears that almost equal numbers of respondents had to evacuation or shelter in place. It also seems that individuals with ID/DD were more likely to evacuate than family members and caregivers in response to the same situations. This result may be related to preparation and support in the event of an emergency.

55.6% (15) reported they thought they would have the support they would need in an emergency, 18.5% (5) said they did not think they would have the support they would need, 25.9% (7) reported that they didn't know. This means that almost half of respondents did not believe that they would have the support that they needed in an emergency event. Examination of the respondents' living arrangement and whether they felt they would have the support they would need in an emergency showed that 27.3% of those who lived by themselves (n=11) did not feel they would have the support they needed, while an additional 27.3% said they didn't know. Among those who lived with family (14), 14.3% (2) said they would not have the support they needed and 28.6% (4) said they didn't know. Two individuals who lived in a community group home reported they felt they would have the support they needed. Although the sample size is small, it appears that individuals with ID/DD in group homes feel comfortable with the level of

emergency support available. Also respondents living with family felt relatively confident in the family's ability to support them in an emergency. Individuals living on their own were less sure of their support network.

Among the 26 participants who responded regarding experience using an emergency plan during a disaster, 42.3% (11) reported that they did not have a plan, 34.6% (9) reported that their plan worked "somewhat", and 23% (6) reported that their plan worked well. This indicates that less than one-third of respondents were completely confident in their emergency plan.

Five individuals reported they had attended emergency planning meetings, three had attended emergency management exercises, and four had attended emergency preparedness classes. All five who attended emergency planning meetings felt they would have the support they need in an emergency. Similarly, those who attended emergency planning exercises and most of those emergency preparedness trainings reported they would have the support they would need. There did not seem to be a relationship between participation in the planning process or training with personal preparedness. Only two of the five respondents who attended emergency planning meetings reported they had a written emergency plan, and two of the three participated in an exercise, and two of the four who participated in a preparedness training had a written plan. It appears that while participation certainly seemed to increase the perception of support it did not translate into concrete personal preparedness action.

When asked if they were interested in participating in emergency planning activities in the future : 17 of 26 responded they were interested in emergency planning meetings, 13 of 23 responded that they were interested in emergency management exercises, and 16 of 24 were interested in emergency preparedness trainings. This shows that a little over half of the respondents want to be actively engaged in emergency planning and are interested in training in emergency preparedness.

Discussion

Across both versions of the survey, the majority of people who indicated that the person with an intellectual or developmental disability would have the support they needed had

previously participated in an emergency planning meeting or emergency preparedness exercise. This may indicate that people who participate in emergency planning activities get a greater sense of the support they (or the person with ID/DD) will receive through their participation, because they were plugged into a support system they were more likely to participate in this type of activity, or that those who participated in these events were more likely to be engaged in the community, and therefore felt they had more support.

The majority of participants in both versions of the survey reported two or more access and functional needs. This finding emphasizes the need for emergency managers to consider a wide array of accommodations they may need to provide in an emergency, and to include those with a range of access and functional needs in the planning process. Some of the needs were not ones that can be readily identified through observation, e.g. medication needs, difficulty understanding information, and sensory sensitivity. This argues for a simple way for individuals to disclose these needs to first responders and shelter staff in the event of an emergency. It also indicates that emergency planning and trainings need to address readiness for multiple functional needs.

Overall, approximately half of respondents indicated interest in becoming part of the emergency planning process. This result may be biased upward because respondents had to be interested enough in the issues of emergencies in the first place to answer the survey; accordingly, the general population of individuals with ID/DD and their family members/caregivers may have less interest than those in the sample. This suggests that there are unmet needs for individual participation in the planning process but that the role of service organizations in representing the full spectrum of individuals with disabilities is still critical.

Clearly individuals with ID/DD living independently in the community are least likely to feel that they have needed support in an emergency. This group is an important population for targeted educational outreach. Family members and caregivers in the community also feel underprepared and should be provided with additional resources for support.

The message that an emergency preparedness plan is important seems to be reaching families, although a non-trivial percentage of respondents do not have a plan and/or need to improve upon the plan that they have. While the need for outreach and education on personal preparedness continues, the potential is there to build upon existing programs or successful messaging strategies.

Recommendations

Inclusion-

All emergency management informants expressed an understanding of the importance of inclusive and whole community planning in the abstract, but identified barriers to implementation of these ideals. One recommendation for these organizations would be to do more to engage people with disabilities directly – rather than through agencies that provide services to people with disabilities - and highlight opportunities for inclusion at local, regional and state level planning meetings and exercises.

While not every individual with a disability can or wants to participate in the same way, there are different kinds of activities and opportunities to participate. These may range from sitting on a planning committee to role-playing in functional exercises. The perception of the role of people with disabilities and access and functional needs in the emergency management community needs to continue to change. The interviewees from organizations who were already including people with disabilities consistently reported that inclusion benefitted their planning process. Rather than concentrating on what people with disabilities might not be able to do in an emergency, organizations at all levels, particularly those who struggle to hire additional personnel or find volunteers with disabilities, should focus on including people with disabilities in any capacity. Since personal relationships seem to play such a strong role in inclusive planning, this has the added benefit of fostering those personal relationships.

The survey indicates that only about 50% of respondents were interested in emergency planning activities, and these respondents are more likely to be predisposed to interest in the issue. Emergency managers should not worry that they are opening the floodgate

and that they will be overwhelmed by volunteers with disabilities! However, there remains the need for emergency managers to learn how to provide accommodations and for community members with disabilities to learn how to participate effectively in order to have their voice heard.

Education-

Given the frequently cited “inconsistency” of awareness and knowledge level on the issue of inclusive planning with people with disabilities across the state, it is recommended that responsible state entities put greater emphasis on working with local, county, and regional partners to implement consistent solutions. If educational programs and inclusive planning programs are supported by or endorsed through PEMA, the Governor’s Cabinet and Advisory Committee for People with Disabilities, and the PA Department of Health, they are likely to have a greater chance of being adapted for implementation throughout the Commonwealth. These educational programs should include information about laws and court cases relevant to inclusive planning, since these have brought attention to the issue and have currency with planners and community members alike. In addition, state mechanisms for financially supporting local and regional emergency planning efforts in providing accommodations would go a long way to easing the anxiety of emergency managers when it comes to inviting community participation. A reliable way to support the provision of accommodations for volunteers with disabilities and access and functional needs will facilitate emergency planning, exercises, and training in environments that are inclusive and welcoming to everyone in the community.

The need to build knowledge and awareness is not limited to emergency management professionals. Service provider organizations and community members play an important role and need to understand the emergency planning process and how outcomes can benefit their organizations and their clients. Survey data clearly indicate that not every individual with a disability has the interest or ability (e.g. due to conflicts with work or transportation difficulties) to engage in emergency planning activities. In that case, service organizations can play an important role both as advocates and as community educators. Accomplishing this will require people with disabilities to develop

a better understanding of all phases of the emergency planning system as well as individual preparedness and business continuity planning. This will create both a common language and a sense that everyone is working together to meet the needs of the whole community.

It is clear from the data that while making sure shelters are accessible is an important issue, the more critical problem that is commonly experienced by individuals with disabilities in the community is a “shelter in place” scenario. Second to that is the need to plan for evacuation to family members and /or friends rather than to a shelter, as the shelter seems to be an evacuation destination of last resort for individuals with disabilities and their families.

Outreach and education to individuals with disabilities and their family members can happen more easily if it is incorporated into already existing services. A significant number of individuals and families lack plans and/or effective plans, and individuals with disabilities living in the community (e.g. independently or with minimal supports) are the most in need of education in order to develop an effective personal preparedness plan and support structure. Where these individuals already have a relationship with a service provider organization, partnerships between the emergency management system and the provider may be a productive approach to personal preparedness education.

References

National Commission on Terrorist Attacks. (2004). The 9/11 commission report: final report of the national commission on terrorist attacks upon the united states including the executive summary. (National Commission on Terrorist Attacks Publication). Washington, D.C.: Government Printing Office.

National Council on Disability (NCD). (2010). Caring for special needs during disasters: what's being done for vulnerable populations?. Washington D.C: Government Printing Office.

Santora, M., & Weiser, B. (2013, November 7, 2013). Court says New York neglected disabled in emergencies. The New York Times.

The Arc. (2011). Introduction to intellectual disabilities. Retrieved September 8, 2013, from <http://www.thearc.org/page.aspx?pid=2448>

US Congress (2004) Individuals with disabilities in emergency preparedness, 13347U.S.C. Vol. 69 No. 142.