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"The Human Rights-Based Approach to Disability in Emergency Preparedness"

A Dissertation presented

by

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Abstract

Over the last few years there has been an evolution in thinking about disability, as demonstrated by the paradigm shift from the medical model to the human rights-based approach (HRBA) to disability. In order to respect the human rights principles, disability needs to be considered in emergency planning of municipalities and long-term care facilities (LTCFs). The results of the study have confirmed and reinforced the importance of building a dialogue on the inclusion of persons with disabilities in emergency preparedness promoted by municipal emergency managers, administrators of LTCFs and citizens themselves. In the context of LTCFs, US and Italian facilities should view physical impaired residents as potential resources during an emergency. Furthermore, administrators of such facilities should provide specific training to their staff to raise the sensitivity to issues of disability. This can provide a positive contribution that can make emergency services more accommodating for the residents of the facility. Finally, US and Italian long-term facilities should immediately clarify that a proactive collaboration in terms of emergency preparation is expected from residents. This would ensure a stronger involvement of the residents in best preparing for an emergency. Also at the municipal level, this study confirms that the inclusion of people with disabilities in emergency preparedness plays a key role in the protection of their rights. People with disabilities are the true experts of their own situations and therefore are in the ideal position to give recommendations on best strategies for including disability needs into disaster preparedness and response. Building a dialogue on the inclusion of people with disabilities in emergency preparedness is crucial to define and share best practices to raise public awareness on the issue of self-protective behaviors, to create strategies along with the civil protection professionals, medical staff, social workers, aimed to enhance the residual skills of persons with disabilities. All these actions would be decisive for a shift from the medical model to the human-rights based approach to disability. Therefore, those involved in disaster management should involve persons with disabilities in the leadership and in decision-making processes.

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Introduction

The World Health Organization (WHO, 2011) estimates that more than one billion worldwide live with a disability, representing about 15 per cent of the world population. The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD, 2006) defines persons with disabilities as individuals *"who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"* (United Nations, 2006). The concept of disability include a multitude of different conditions, which can reduce a person's ability to participate to some extent in the regular societal activities, or at least to do so without significant help from equipment, medication or caregivers (Alexander and Sagramola, 2014). Throughout history, there has been an evolution in thinking about disability, as demonstrated by the paradigm shift from the medical model to the social model of disability, recently supplemented by the Human Rights-Based Approach (HRBA). According to Klasing (2011, p. 85), the new approach introduced by the CRPD *"moves from the treatment of persons with disabilities as objects of medical treatment and social protection, towards viewing those persons as people with rights, capable of being active members of society".*

In situations of emergency, persons with disabilities are disproportionately affected due to their often highly vulnerable physical, mental, intellectual or sensory conditions (Ito, 2014). Recent events have brought worldwide attention on the experiences of persons with disabilities during disasters (Stough & Kang, 2015). For example, during Hurricane Katrina in 2005, elderly individuals drowned in their wheelchairs and beds inside St. Rita's Nursing Home as floodwaters rose around them (Stough & Kang, 2015). Furthermore, according to emergency management statistics, when natural disasters strike, people with disabilities tend to die in far higher percentages of the population than other people (Reinhardt et al., 2011). The Convention on the Rights of Persons with Disabilities specifically addresses the rights of persons with disabilities in situations of risk and humanitarian emergencies. Under Article 11, the CRPD mandates that *"all necessary measures, including those taken through international cooperation, ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters".* The Convention also stipulates that *"States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis*

of disability" (Article 4.1) and *"recognizes the importance of international cooperation to address the limited capacities of some States to respond to situations of risk and humanitarian crises"* (Article 32). The Third World Conference on Disaster Risk Reduction (WCDRR), held in Japan in 2015, represented a unique opportunity to address the invisibility of persons with disabilities in current approaches to Disaster Risk Reduction (DRR), and to ensure that priority is given to this issue in order to fill the gap between policy and practice (Ito, 2014). The inclusion of disability perspective in this important document firmly establishes persons with disabilities and their advocacy organizations as legitimate stakeholders in the design and implementation of international disaster risk reduction policies (Stough & Kang, 2015). Despite the efforts made by the United Nations to ensure the inclusion of disability perspective in the Disaster Risk Reduction Framework (DRRF), progresses in this field are still very low. At this regard, Alexander and Sagramola (2014) stressed that, when an emergency occurs, persons with disabilities have the right to receive the same level of protection as is given to other individuals and, moreover they must receive a kind of assistance that avoid situations of disadvantage or discrimination. In order to ensure that the rights and needs of persons with disabilities are not ignored during situations of emergency, it is crucial to promote participatory strategies for including persons with disabilities in the emergency preparedness process and enhancing their capacity to respond to an emergency. Although several studies highlighted the need for a greater inclusion of persons with disabilities in emergency preparedness, the importance of the human rights-based approach have been recognized worldwide by many countries and local communities as well. According to Rouhban (2014, p.82) some programs and initiatives, implemented at local, national and international level, helped provide "*the means for communities, countries and groups of nations to learn and acquire knowledge, and to enhance the application of this knowledge in coping with the threats to their built and physical environment".* These examples of good practices should serve as a source of inspiration for other countries to emulate and adjust to their own circumstances and needs.

This study was co-founded by the Istituto Santo Stefano Riabilitazione (Porto Potenza Picena, MC) and the Università Politecnica delle Marche and stems from the necessity of the Civil Protection Department of the Marche Region (a small region on the East coast of central-east part of Italy) and of the Disaster Research Center (University of Delaware, USA), to investigate, respectively, on how Italian municipalities and US and Italian long-term care facilities (LTCFs) are dealing with the issue of disability in emergency situations. Another reason for this study concerns the availability of information on people with disabilities at local level, how they are identified within communities and what are the major challenges that impede an inclusive approach to emergency planning and management activities. Also the

level of knowledge and perception of disability issue has been considered for this study namely administrators and healthcare staff of LTCFs, and local emergency managers know how to approach to disability-related issues and how they are preparing to support and assist people with disabilities and their families in case of emergency.

Chapter 1 will provide an overview of various disability-related issues in emergency preparedness. The role played by the UN Convention on the Rights of Persons with Disabilities in protecting and promoting the rights of those persons in situations of emergency will be investigated as well as shortfalls in international policies with respect to the Convention. Chapter 1 will report various negative issues experienced by persons with disabilities following Hurricane Katrina and Haiti earthquake as well as some successful disability-inclusive strategies in disaster preparedness and response.

Chapter 2 will provide the results of the interviews conducted with the emergency management officials of three municipalities of Marche region. The study aimed to understand at which extent the needs of persons with disabilities were included in the municipal emergency plan and if those persons and their families were included in the emergency preparedness process. Furthermore, the results of the study were used to support the Department of Civil Protection of the Marche Region in developing guidelines for assisting persons with disabilities during situations of emergencies.

Chapter 3 focused on the differences between US and Italian staff in terms of emergency preparedness. Often affected by physical, cognitive and psychological disabilities, residents of long-term care facilities must rely on the aid of staff, drugs, and medical equipment on a daily basis and, in case of emergency, they rely on the ability of the staff to safely execute emergency and evacuation procedures. Therefore, the emergency preparedness process of the selected facilities was investigate in order to understand how they address the needs and the rights of the residents in situations of emergency. The interviews with the administrators of the facilities included some significant disability-related issues such as evacuation procedures, safe patient handling techniques, transportation and communication systems, collaboration with external emergency management agencies and specific federal and state regulations on how to include residents and their families in emergency planning, training and practical exercises. Special attention was paid to a practical exercise conducted by Lega del Filo d'Oro, an Italian rehabilitation institute for children and adults with visual, hearing and cognitive disabilities. The earthquake response drill involved all the staff and residents, the Civil Protection Department of the Marche Region, the emergency management officials and the local first response teams (e.g., fire fighters, red cross, local

police etc.). Given that the residents of the facility had serious cognitive deficits, the administrator stressed the importance of a continuous dialogue on emergency-related issues between the staff and residents' families. In this sense, the facility distinguished itself for a more inclusive and integrated approach to emergency preparedness. The important findings emerged during the debriefing exercise have been reported and discussed.

Each chapter contains a general introduction, the aim of the study and research questions as well as a complete description of the methodology used for the analysis.

Chapter 1: Literature Review

1.1 Definition of disability: evolving perspectives

More than one billion people all over the world live with a disability (including children and older people), representing about 15 per cent of the world population. Disability can be considered part of the human condition and almost every persons will be temporarily or permanently impaired at some time in their lives (World Health Organization, 2011). Every epoch has faced the moral and political concern of how best to include and assist people with disabilities into society and the issue will become more urgent as the demographics of societies change and the human lifespan increases (Lee, 2003). Recognizing the presence of negative attitudes towards people with disabilities is crucial for a variety of reasons. For example, in the context of work environment, when there are low towards people with disabilities, employers may be less likely to hire them. On the other hand, if people with disabilities feel that they are stigmatized, this can lead to a cycle of dependency and exclusion, turning the negative perceptions into a self-fulfilling prediction (Rieser, 2000).

Societies have approached the issue of disability in different ways over the time. The different approaches (or models) to disability symbolize how persons with disabilities are treated in society and, furthermore, they represent conceptual frameworks for understanding disability and why certain attitudes exist as well as how these attitudes are reinforced in society. Farther, these models are in turn reflected in and perpetuated by the normative system. For a long time, disability was mostly perceived as a mythological or religious issue (e.g. persons with disabilities were considered to be possessed by devils or punished for past wrongdoing) and these interpretations are still present today in many traditional societies. Later, in the nineteenth and twentieth century's, progresses in science and medicine lead to recognize the biological and medical basis of disability. According to this approach, also known as *"medical model",* the impairments in body function and structure of persons with disabilities are strongly related to the different health conditions of the individual. The medical model focuses on the assistance and the provision of medical care by doctors and disability professionals and therefore people with disabilities have largely been supported in the past through solutions that segregated and abandoned them, such as residential institutions and special schools (Parmenter, 2008). Such mechanisms of isolation reflected the negative societal attitudes held toward diversities. Even today, people with disabilities are often perceived as

"different" or "special" and are frequently attributed stereotypical characteristics such as weakness, dependency, and incapacity (Sullivan, 2011). At this regard, (Roth, 2014, pp. 107-108) explained that *"when people with disabilities are thought of as "special", they are often thought of as marginal individuals who have needs, not rights. The word "vulnerable" has a similarly unfortunate effect. Vulnerable people must have things done for them; they are recipients, not participants"*. Looking at the legislative implications of the medical model, Harpur (2012) stressed that policies guided by this model try to fix the physical or mental state of individuals rather than focusing on other key public issues (e.g., providing support to enable the persons to exercise their rights). Good evidence of this can be found in policies that invest resources to help people in wheelchairs walk, while current construction standards do not require buildings to have lifts and ramps.

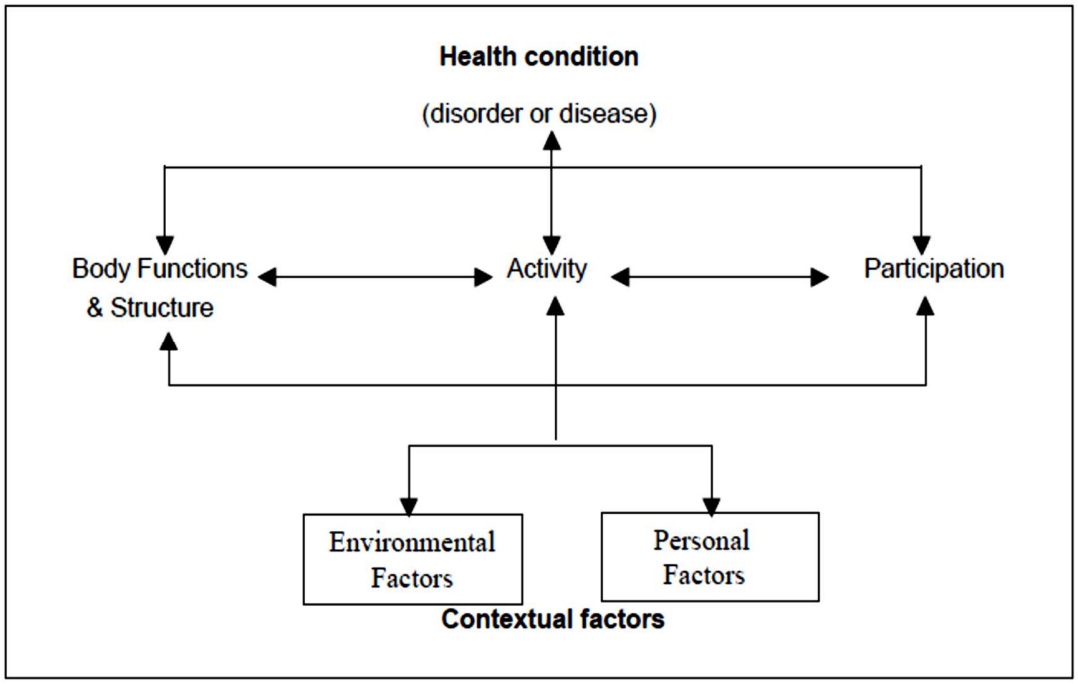
Only since the 1970s, responses to disability-related issues have changed. New studies on social model began to spread in the United Kingdom and, later, the Disabled People's Movement (DPO) (Charlton, 1998; Driedger, 1989), together with various researchers from the social and health sciences (Barnes, 1991; McConachie et al., 2006), have started to investigate how social and physical barriers could affect the lives of persons with disabilities. In 1974, the Union of Physically Impaired Against Segregation (UPIAS) was formed by people with disabilities and began to promote the inclusion of those persons into societal activities. Among various initiatives, UPIAS wrote a paper called *"Fundamental Principles of Disability"*. This momentous document set out the ideas that are now called the *"social model"* (The British Council of Organizations of Disabled People, 1997). The so-called social model of disability shifted the focus away from the medical aspects and instead posed attention to the barriers that persons with disabilities commonly face during their daily experiences. The transition from a medical perspective to a social perspective has been described as the shift from the medical model to the social model in which people are viewed as being disabled by society rather than by their impairments (Oliver, 1990). Leonardi et al. (2006) explores this concept giving some examples of how the environment can affect a person with disabilities: a deaf individual without a sign language interpreter, a wheelchair user in a building without an accessible bathroom or elevator or a blind person using a computer without screen-reading software. Therefore, the social model aimed to eliminate all physical, organizational and attitudinal barriers and to move society from treating persons with disabilities as *"defective"* towards being more inclusive.

According to Thomas (1999), although the medical and social model are often presented as dichotomous, disability should be viewed neither as purely medical nor as purely social. Disability, in fact, is a complex

phenomenon where characteristics of the person intersect features of the environment in which the person lives. Therefore, both medical and social models are appropriate to address disability-related issues and an integrated approach is needed in order to consider all different aspects of disability (Forsyth et al., 2007; Shakespeare, 2006).

Over the time, the World Health Organization (WHO) developed many classification tools to refer to the concept of health and disability, up to the *"International Classification of Functioning, Disability and Health"* (ICF) of 2001. The *"bio-psycho social model"* of disability, based on the ICF, represents a valid compromise between medical and social approaches (World Health Organization, 2002). The ICF was developed through a long process involving academics, physicians, and, most importantly, persons with disabilities (Bickenbach et al., 1999). The ICF emphasized environmental factors in creating disability, which is the main difference between this new classification and the previous *"International Classification of Impairments, Disabilities, and Handicaps"* (ICIDH) of 1980. As already mentioned, ICF represents the conceptual basis of the bio-psycho social model of disability (see figure 1.1.1). According to this model, disability and functioning are the results of interactions between health conditions such as disorders and injuries, and contextual factors. Contextual factors include *external environmental factors* (e.g., social attitudes, architectural characteristics, legal and social structures, etc.) and *internal personal factors* (e.g., gender, age, education, past and current experience that influence how the individual experiences disability, etc.). Among the environmental factors, policies and service delivery systems can also be considered as barriers (Miller et al., 2004). In Europe, an analysis of access to health care services revealed that some organizational issues (e.g., waiting lists, lack of a booking system for appointments) may represent a barrier for persons with disabilities (Scheer et al., 2003; Smith, 2000). Societies can also indirectly excludes persons with disabilities by not considering their needs in the appropriate way and therefore, the role of institutions and organizations is significant in order to avoid situations that exclude and further marginalize people with disabilities. Finally, negative attitudes are also significant environmental factors and may lead to negative consequences on the lives of persons with disabilities such as low self-esteem and reduced participation in societal activities (Thornicroft et al., 2007). Therefore, people who feel harassed because of their disability, sometimes avoid going to places or even moving from their homes (Disability Rights Commission, 2004).

Figure 1.1.1: Representation of the bio-psycho social model of disability



Source: World Health Organization (2002)

Although the undeniable importance of the social model in raising awareness and challenging negative attitudes towards disability, some authors, such as Shakespeare (2006), have raised concerns that the social model failed to explain the significant role that impairments may have upon individuals that is. The general idea of the author is that impairments may affect people even if society remove barriers. Therefore, an accessible environment reduces the inconvenience of impairments but does not ensure equality to people with disabilities (Shakespeare, 2006). According to Harpur and Bales (2010), approaching disability as a human rights issue can support theories of disability to be better aligned with practice.

According to the World Health Organization (2011, p. 9), disability can be considered a human rights issue when, for example, *"people with disabilities are denied equal access to health services, employment, education, or political participation because of their disability. People with disabilities can also suffer violations of dignity when they are subjected to violence, abuse, prejudice or disrespect because of their conditions*". A significant number of international documents have defined disability as a human rights issue, including the World Programme of Action Concerning Disabled People (United Nations, 1982), the Convention on the Rights of the Child (United Nations, 1989) and the Standard Rules on the Equalization

of Opportunities for People with Disabilities (United Nations, 1994). In 1990, the US government passed the Americans with Disabilities Act (ADA) that gave people with disabilities real and enforceable rights. In 2001, the United Nations General Assembly established an Ad Hoc Committee to report on the possibility of the United Nations adopting a disability-specific human rights convention. The process resulted in the Convention on the Rights of Persons with Disabilities (CRPD) that has been presented to the General Assembly on 5 December 2006. On 13 December 2006, the UN General Assembly unanimously adopted the CRPD. Article 1 of the Convention defines disability as *"long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder people's full and effective participation in society on an equal basis with others"*. The Convention aims to *"promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities and to promote respect for their inherent dignity*" (CRPD, art. 1). It is important to note that the CRPD is based on already existing human rights principles, primarily the fundamental right of non-discrimination. Under article 2 of the Convention, discrimination is defined as "*any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation"*. With the term *"reasonable accommodation"*, the Convention refers to any *"necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms*" (CRPD, article 2). This concept is extremely important because requires that peculiarities of persons with disabilities are taken into account to prevent indirect discrimination. In practice, it means that a person with disabilities, for example, can reasonably discuss with his/her employer in order to decide, after considering all the circumstances of the case, the most suited work placement. The CRPD introduces a new disability rights paradigm also known as "*the human rights-based approach to disability"*. According to (Klasing *et al*. 2011, p.85), "*the overall role of a rights-based approach is to strengthen the opportunities for rights holders to claim their rights and the capacity of duty-bearers to respond to such claims and fulfil rights"*. At the basis of the rights-based approach, there is the idea that the entire population of a country can benefit from the promotion of human rights.

Today nearly all European countries and the European Union itself have ratified the UN Convention on the Rights of Persons with Disabilities (UN CRPD) and thus have committed themselves to its implementation *"with all available resources"* (European Association of Service Providers for Persons with Disabilities, 2014). A study on *"Challenges and Good Practices in the Implementation of the UN Convention on the Rights of Persons with Disabilities"* was conducted by the European Foundation Centre (2008). The study aimed to collect information about the various practices for implementing the Convention by the European Union (EU) and its Member States. Furthermore, the study intended to identify challenges that may hinder the full and effective implementation of the Convention and *"good practices"* that would facilitate the achievement of its goals (European Foundation Centre, 2008). Some of the major challenges and suggestions for the implementation of the Convention at both the EU and Member States level are summarized below:

***Uneven Implementation of the Paradigm Shift*:** although the EU legislation is formally based on a rights-based approach, further progresses have to be made in order to put in practice the shift towards a social model of disability. The new paradigm should be reflected in the overall statement of guiding principles for laws and policy reforms. Furthermore, EU legislation should represent an effective guidance for the Member States on how to approach disability and how to effectively implement the principle of equal treatment and equal opportunities (European Foundation Centre, 2008, p.1).

Lack of National Screening: since most of the defaulting EU Member States have not yet reviewed their national legislation in order to implement the CRPD, the EU has identified the existing legal instruments related to issues covered by the Convention. However, these instruments are not sufficient to guarantee an effective implementation of the CRPD, but they must be accompanied by an activity of national screening aimed to modify existing legislation that does not comply with the Convention (European Foundation Centre, 2008, p. 1-2).

***Uneven Reach of Non-discrimination Laws*:** EU and Member States legislation on equality and non-discrimination exist mostly within the context of employment. However, significant challenges are related to the fact that several Member States do not address the denial of reasonable accommodation as an explicit form of discrimination and to the lack of laws addressing multiple-discrimination (e.g., women with disabilities). Therefore, the EU and Member States should explicitly address the issue of multiple-discrimination in compliance with Articles 6 and 7 of the Convention. In addition, considering that multiple-discrimination is a fairly new issue in the area of non-discrimination, the EU and Member States

should promote research activities in order to identify legal instruments that restrict the negative effects of this specific form of discrimination, in compliance with the objectives set forth in the Convention (European Foundation Centre, 2008, p. 2).

***General Accessibility*:** although the EU Member States have included in their national laws the principle of accessibility, this is not enough to guarantee the effective implementation of the CRPD. For issues related to general accessibility, the EU and the Member States should strengthen their cooperation in order to ensure that the principle of accessibility applies to different sectors such as employment, education, transport, justice, etc. in compliance with It well-established accessibility requirements and standards. Accessibility measures should also include a clear timeframe for conformity as well as establish a financial section mechanism in cases of non-compliance (e.g. financial sanction). A good practice suggested by the EU is the development of universally designed services and facilities that would reduce, or even avoid, the costs of the subsequent dismantling of physical barriers (European Foundation Centre, 2008, p. 2).

***Independent Living - Using that Voice to Choose How to Live*:** the existence of national laws that still permit institutionalization of persons with disabilities represent an obstacle for their social inclusion and full participation in society. Several national policies focus on how to improve institutional care, instead of relocate residents of such institutions into the community. In cases where national policies promote independent living for persons with disabilities, the frequent absence of direct payments aimed to allow persons with disabilities to manage their own affairs is a significant challenge to the effective implementation of the CRPD. With regard to the EU, many instruments exist for the functioning of the internal market (e.g., indirect taxation and state aid), which are relevant to Article 19. These instruments could positively contribute to the elimination of barriers (such as inaccessible, or insufficient, goods and services) for persons with disabilities to fully enjoy the right to independent living. The EU Member States should implement direct payment or individualized funding mechanisms to permit persons with disabilities to manage their own lives. Member States should also establish community based services, adequately funded and sufficiently resourced, for the provision of the required hours of personal assistance to support the living needs and inclusion of persons with disabilities in all aspects of society (European Foundation Centre, 2008, p. 3).

Employment - Earn a Living by Work freely chosen or accepted in the labor market: the Employment Equality Directive 2000/78/EC, have highly influenced the EU Member States that have prohibited, by law, discrimination on the basis of disability within the context of employment and have established

provisions for reasonable accommodations for persons with disabilities. Nonetheless, many obstacles to the effective implementation of the CRPD have to be challenged. The study of the European Foundation Center has revealed an inconsistent interpretation of key concepts such as "discrimination" and "reasonable accommodation". In addition, since the Directive 2000/78/EC does not explicitly refers to an unjustified denial of reasonable accommodation as a form of discrimination, many Member States have not done so either. Finally, existing legislation seems to be not effective in practice given the poor implementation of employment quotas and low participation rates in the labor market for persons with disabilities. Then, the EU and Member States should ensure that legislation does not limit the scope of the duty to provide reasonable accommodation, which, should be extended to all areas of social, political, civil and economic life (European Foundation Centre, 2008, p. 3-4).

Education - Full Development of persons with disabilities' potential to participate effectively in society: few efforts have been made yet to move towards the provision of an inclusive education in compliance with the principle of equal opportunity. In fact, the option of sending children with disabilities to special educational facilities is not only permissible but also favored in many cases. This is a significant challenge to the full and effective inclusion of children with disabilities in the education system. Furthermore, in many cases, the lack of resources available to provide specific services and specialized training for teachers are also major challenges. Hence, the EU Member States should guarantee a common learning environment free of all forms of discrimination (European Foundation Centre, 2008, p. 4).

Uneven Participation in Political and Public Life: although most of the EU Member States have adopted legislative instruments to ensure the participation of persons with disabilities in voting procedures, these are not sufficient to ensure full and effective inclusion of persons with disabilities in political and public life. By way of example, in many cases ballots and general information about the elections are not available in alternative formats (e.g. Braille or easy-to-read formats). Research conducted by the European Foundation Center has revealed that the majority of the EU Member States have created consultative disability forums with the purpose to ensure the participation of persons with disabilities in public life. However, little information is available in relation to the usefulness of such forums (European Foundation Centre, 2008, p. 4).

Lack of Training: there is an urgent need for both the EU and its Member States to develop training programs for professionals from different sectors (e.g., judges, lawyers, public administrators, architects, engineers) with the purpose to raise awareness about the matters covered by the CRPD. Obviously, such

programs should be accessible to people with disabilities and representatives from organizations of those persons (European Foundation Centre, 2008, p. 5).

***Insufficient Disability-specific Statistics and Data*:** the study of the European Foundation Center could not identify adequate information, within the Member States of the EU, about practices related to the collection of statistics and data useful to support policy development and the monitoring of policy implementation. Consequently, further research in this field is needed. It is necessary to review existing instruments and evaluate whether (or not) such instruments are appropriate for the compilation of disaggregated data on disability. For this reason, existing methodological tools should be tested, and if necessary should be modified, with the aim to ensure their efficiency (European Foundation Centre, 2008, p. 5).

On 27 and 28 of August 2015, the European Union was examined for the first time by a UN human rights committee in Geneva (the expert Committee on the Rights of Persons with Disabilities). The EU, which has ratified the CRPD in 2010, was called to present the work made on the implementation of the Convention since then (Equinet European Network of equality bodies, 2015). Recently, the UN Committee published its concluding observations and recommendations on how the EU can promote and protect the rights of persons with disabilities in Europe such as to adopt a comprehensive strategy to implement the Convention across all EU institutions (Equinet European Network of equality bodies, 2015). All these recommendations are the basis for the beginning of an important period as emphasized by the President of the EDF, Yannis Vardakastanis, who expressed words of pride and encouragement about the work made by the EU and its Member States on the implementation of the CRPD: *"This is a historic moment for us. People with disabilities across the European Union have been hit hard by austerity, and face increasing poverty and marginalization. Today, the UN expert committee has recognized this, and has provided a powerful and comprehensive set of recommendations to the EU. This gives a strong mandate to the EU, including all its institutions and agencies to fully address the inclusion of persons with disabilities in all of their work. The EU has been a world leader in committing as a regional body to this human rights Convention. It can also be a leader in the implementation of the Convention"* (Christian Blind Mission, 2015). The EU has a follow-up review in 4 years time. It will have to explain at that moment which steps it has taken to implement the recommendations. The next progress report has to be submitted by January 2019. The European Disability Forum together with its members and partners, including the Christian Blind Mission (CBM) and colleagues of the International Disability

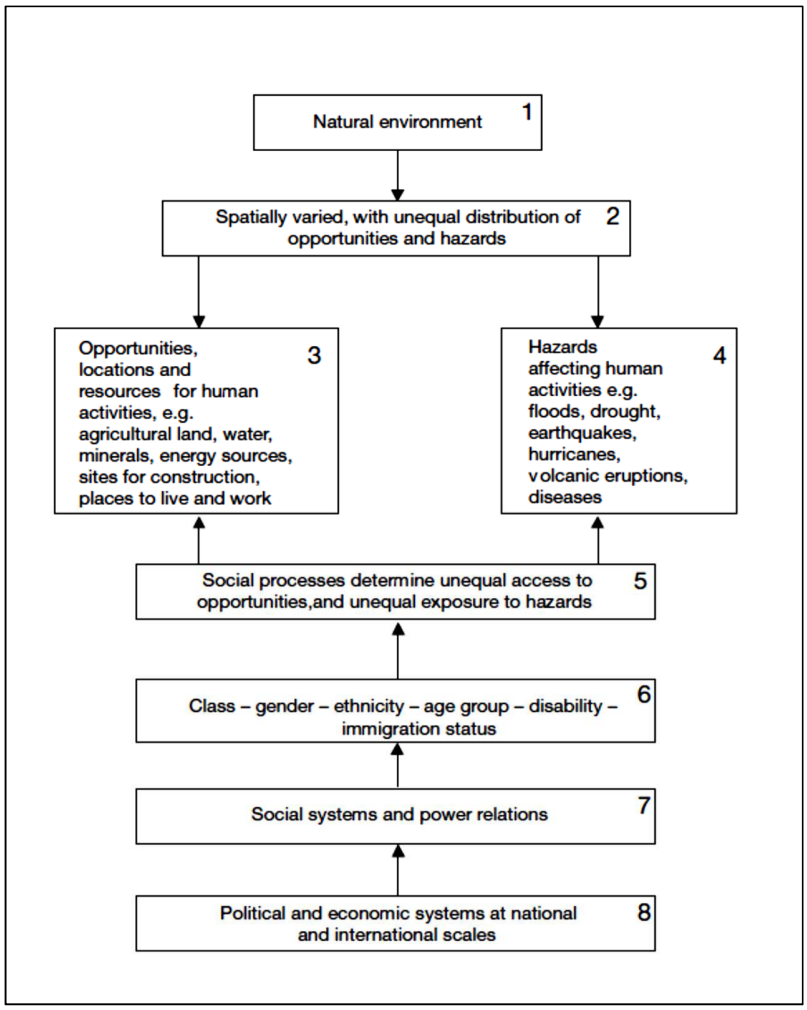
Development Consortium (IDDC), will continue working actively to promote the Convention for the coming 4 years based on the UN's concluding observations (Christian Blind Mission, 2015).

It has been observed that a human rights approach is often appealed when issues of who is the most deserving, or the most vulnerable arise. In situations of emergency, persons with disabilities are often extremely affected due to the lack of access, information and support services. Next chapter will focus on inequalities that persons with disabilities commonly face in disaster situations and the factors that can increase the vulnerability of persons with disabilities to the adverse impact of hazards. In addition, some available evidences of the benefits of disability-inclusive approaches will be discussed.

1.2. Disasters And Disability

Disasters are of increasing concern for humankind, due to their frequency, complexity and destructive capacity. Wisner *et al*. (2003) explained that there is an inadequate way of understanding disasters that are associated with natural hazards. According to the authors, natural environment offers to humankind a range of opportunities (resources for production, places to live and work as well as a range of potential hazard) but humans are not equally able to access the resources and opportunities, nor are they equally exposed to the hazards. Many social factors play a key role in determining who is most at risk from hazards such as class, gender, ethnicity, age, whether persons have some disabilities or not (see figure 1.2.1).

Figure 1.2.1: The social causation of disasters



Source: Wisner *et al*. (2003)

Therefore, to understand disasters, we must know the different levels of vulnerability of different groups of people. Wisner *et al*. (2003, p. 11) defined vulnerability as "*the characteristics of a person or group and their situation that influence their capacity to anticipate, cope with, resist and recover from the impact of a natural hazard*". In the 1990s research attention started to include a broader range of vulnerable groups of people, including persons with disabilities. For example, after Hurricane Floyd in 1999, (Willigen et al., 2002) discovered that persons with disabilities wanted to respond to warnings but did not a person who supported their evacuation. In addition, those persons perceived that shelters would not adequate in accommodating their needs (Phillips & Morrow, 2007). More recently, in 2005, Hurricane Katrina affected an estimated 155,000 persons with disabilities in the cities of Biloxi, Mobile and New Orleans (National Council on Disability, 2009). According to the White House (2006) the most vulnerable residents suffered terribly from Hurricane Katrina's impact and inadequate or nonexistent evacuation operations.".

A study conducted by Smith *et al*. (2012, p. 4) found that both published and grey literature have focused on the issue of *"disability-related inequalities during disasters"*, which include: *"(1) availability of information and knowledge on disability-related issues; (2) involvement of persons with disabilities in disaster management and relief aid processes; (3) availability of physical environments and preparedness measures and relief aid; (3) stigma and discrimination"*. Evidences of these inequalities have been found by Njelesani *et al.* (2012), in their study "*Using a Human Rights-Based Approach to Disability in Disaster Management Initiatives*. Njelesani *et al.* (2012) investigated the disaster management initiatives of the 2010 Haiti Earthquake and the 2005 Hurricane Katrina from a human rights perspective, focusing on some principles of the Convention on the Rights of Persons with Disabilities. The authors found that during Hurricane Katrina and Haiti Earthquake (see Figure 1.2.2) there was a lack of coordination between disaster response organizations and associations of persons with disabilities. Furthermore, those persons and their representative organizations were not consistently involved in disaster planning and camp coordination meetings. In the specific case of Haiti, for example, non-governmental organizations had a separate *"Injury, Rehabilitation and Disability Working Group"* which seldom included persons with disabilities. Also in the case of Katrina, the disaster plans failed because the organizations providing services did not sufficiently encouraged persons with disabilities to participate in emergency planning meetings. According to the National Organization on Disability (2009), in some cases, information was not accessible in alternative formats and therefore, persons with hearing impairments were not able to use

phones to contact their family members or arrange for housing as well as persons with visual impairments were not able to access information only distributed in flyers.

Another key issue stressed by the authors is the importance to consider the variety of needs related to different disabilities. In Haiti, for example, fewer services were available for persons with psychological impairments or mental disorders. Government mental health services were, in fact, limited to two mental hospitals located in the West Department and the Ministry of Health and Population did not have any mental health units at general hospitals (PAHO, 2010). Furthermore, in the case of Katrina, the needs of individuals with cognitive disabilities were not adequately addressed and many people were separated from their caregivers. The evacuation plans for Hurricane Katrina were not properly developed for persons with disabilities that is many evacuation transports did not have wheelchair lifts and many persons with disabilities were often evacuated without their medical supplies or personal assistance devices. In addition, considering that most people in the United States received emergency information about the storm from the television, the communication was not accessible to persons with sensory disabilities. Njelesani *et al*. (2012) with their study demonstrated that persons with disabilities were not included in disaster management initiatives of Haiti Earthquake and Hurricane Katrina. Oher studies the inclusion of disability into disaster response activities have demonstrated similar findings (IFRC, 2007). The reasons of this repeated discrimination in the face of international conventions and treaties as well as civil rights laws, may include the perspective that disability is a specialized field and that accommodating for disability entails increased the need of financial resources and time (IFRC, 2007; Handicap International, 2010).

Marcie Roth (2014), the Senior Advisor and Director of the Office of Disability Integration and Coordination (ODIC) of the Federal Emergency Management Agency (FEMA), explained that, during the terrorist attack on the United States on September 2011 and Hurricane Katrina in 2005, "*the needs of persons with disabilities were treated as "special" and led to separate planning strategies and efforts. This rendered the preparedness, response and recovery needs as an afterthought, rather than a key element of a robust plan to meet the needs of the whole community to prepare for, protect against, respond to, recover from and mitigate all hazards"* (Roth, 2014, p. 105)

Figure 1.2.1.: The earthquake in Port-au-Prince, Haiti

Source: United Nations, 2010

Roth (2014) agreed with Njelesani *et al*. (2012) about the fact that emergency management officials, community-based organizations and disability community leaders are not adequately aware of one another or coordinated during disaster management activities. This is demonstrated by the fact that nearly 86 per cent of the organizations providing services to people with disabilities in the Gulf Coast region (before Katrina) did not know the name of their local emergency managers (National Council on Disability, 2009). In order to achieve a disability-inclusive emergency management ODIC developed a set of key non-discrimination concepts (mentioned below) with examples of how these concepts should be applied to all phases of emergency management (Roth, 2014, p. 114):

Self-determination: *people with disabilities are the most knowledgeable about their own needs. Thus, people have the right to choose or refuse the assistance they are offered;*

No "one-size-fits-all": *people with disabilities do not all require the same assistance and do not have the same needs;*

Equal opportunity: *people with disabilities must have the same opportunities to benefit from emergency programmes, services and activities as people without disabilities;*

Inclusion: *people with disabilities have the right to participate in and receive the benefits of emergency programmes, services and activities provided by governments, private business and non-profit organizations;*

Integration: *the provision of services such as sheltering, information intake for disaster services and short-term housing in integrated settings keeps people connected to their support system and personal assistance services providers and avoids the need for disparate services facilities;*

Physical access: *emergency programmes, services and activities must be provided at locations that all people can access;*

Equal access: *people with disabilities must be able to access and benefit from emergency programmes, services and activities equal to the general population;*

Effective communication: *people with disabilities must be given information that is comparable in content and detail to that given to the general public;*

Programme modifications: *people with disabilities must have equal access to emergency programmes and services, which may entail modifications to rules, policies, practices and procedures;*

No charge: *people with disabilities may not be charged to cover costs of measures necessary to ensure equal access and non-discriminatory treatment.*

Alexander and Sagramola (2014) reported many lacks in the implementation of the Convention on the Rights of Persons with disabilities in the context of emergency management across Europe. The authors stated that lack of a registration system for people with disabilities is one of the most significant shortcomings. Article 31 of the Convention, which deals with data collection, stresses the importance of respecting the privacy of persons with disabilities. Therefore, the privacy issue must be addressed by states and local governments in order to be able to collect systematic data of persons with disabilities (e.g., addresses, types of disability, specific medical and food supplies) without violate the privacy laws. The register needs to be available to local authorities and to be kept updated in order to be usable when an

emergency occurs and especially during the development of emergency plans, as it will contain valuable information for local emergency planners and managers. Another issue addressed by Alexander and Sagramola (2014, p. 22) is the WHO International Classification of Functioning, Disability and Health (ICF), which is applied by many states to distinguish between the medical and social approach to disability. These specific issues as well as other factors that lead to situations of disadvantage and discrimination for persons with disabilities, need to be addressed by the legislation. However, as well explained by Alexander and Sagramola (2014, p. 22), *"specific measures should not over-concentrate responsibility in single organization, leading others to relinquish their roles in caring for people with disabilities"*. On the other hand, it is crucial to define the responsibilities of the various organizations and institutions involved in caring persons with disabilities during disasters. This is important, for example, for long term-care facilities that have their own emergency plan. *"The failure to implement legislation and develop standards and guidelines is commonly attributed to lack of financial resources but it can also mean a lack of political or administrative motivation to find resources*" (Alexander and Sagramola, 2014, p. 22). Lastly, *"a serious rethink of priorities when defining policies that allocate public or civil society (NGO) funds is needed. In fact, civil protection agencies and local governments may be reluctant to devote funds destined for emergency preparedness to a single sector of the population"* (Alexander and Sagramola, 2014, p. 23).

Providing an adequate level of protection to persons with disabilities in situations of emergency is a serious issue. Available structures, organization and resources need to be properly designed and adequate to accommodate the needs of persons with disabilities and to assist those persons in emergency. Many countries are improving their emergency preparedness but more efforts should be made in order to include people with disabilities into decision-making processes as well as in training and practical exercise. Many remarkable activities have been carried out on this important issue. One of these is the *"Living with disabilities and disasters",* a global initiative of the UNISDR 2013 International Day for Disaster Reduction that is designed to promote resilience and disability-inclusive risk reduction strategies. The Council of Europe's Disability Action Plan 2006-2015 (Council of Europe, 2006), promotes the rights of people with disabilities and aims to support them to improve their quality of life by *"meeting country-specific conditions as well as transition processes that are taking place in various member states […] and is intended to serve as a roadmap for policy makers, to enable them to design, adjust, refocus and implement appropriate plans, programmes and innovative strategies"*.

Another remarkable initiative is that of the Council of Europe that in 2013 disseminate a questionnaire on disaster risk reduction and emergency preparedness for people with disabilities among all 26 member countries of the European and Mediterranean Major Hazards Agreement (EUR-OPA) and other members of the Council of Europe (EUR-OPA, 2013). The results of the survey revealed that, although the participating nations are improving their emergency preparedness, "*the level of provision for people with disabilities is relatively low as well as there is little or no uniformity in the measures adopted and these are highly variable in their reach, effectiveness and level of implementation. There is also a tendency for responsibilities to be split between ministries and agencies, and for there to be no guarantee that communication and collaboration will be sufficient to produce viable measures"* (Alexander and Sagramola, 2014, p. 33). However, some examples of good practice do exist and these include the creation of specific offices that address the issue of disability in situations of emergency ensuring that the problem is adequately faced by national policies. For example, Bulgaria has identified a senior member of government who is responsible for coordinating policy, plans and measures in favour of people with disabilities in emergency. Furthermore, EU fundings were used to create a register of people with disabilities because, although the structure of disaster planning was well developed in Bulgaria, the provisions were not specific for people with disabilities. In Belgium and other countries, text messages have been used to alert deaf people in case of emergency and in Norway, hospitals, nursing homes and healthcare staff have a general obligation to evacuate persons with reduced mobility in emergency. In Greece people with specific needs in schools are given an e-lesson under the programme "*E-learning about earthquake protection for people with disabilities*" of the European Centre on Prevention and Forecasting of Earthquakes. The Republic of Serbia has developed a pilot project to enable people with hearing and speech impairments to contact the emergency services on emergency numbers in case of need. A Centre for Disability Studies exists at the University of Leeds in the United Kingdom, and its researchers have conducted studies related to disaster preparedness. Furthermore, a project called *"European Network for Psychosocial Crisis Management - Assisting Disabled in Case of Disaster"* (EUNAD) was developed to evaluate networks of associations for people with disabilities in terms of their levels of preparedness for disasters, to conduct further studies and to organize workshops (Alexander and Sagramola, 2014, pp. 34-35). *There have been significant developments outside Europe from which member countries of the EUR-OPA Agreement could derive inspiration. In New Zealand, for example, disaster services such as emergency call centres have been made accessible to persons with disabilities and firefighters have created a unit in which officers speak sign language. In the United States, the Federal Emergency*

Management Agency (FEMA) has dedicated part of its website to information resources for people with disabilities (FEMA, 2013). The documentation offers advice and know-how to such people and explains projects connected with improving the access and support for disabled survivors of Hurricane Katrina (Alexander and Sagramola, 2014, p. 35).

Also Rouhban (2014) reported many initiatives outside Europe in post-disaster situations. Following the floods that devastated Bangladesh in 2004 and the giant cyclone Sidr, which affected the country on 15 November 2007, approximately 60 per cent of persons with disabilities were not adequately support in post-disaster interventions and 11 per cent of the people who sustained injuries became permanently disabled. From October 2009 to June 2011, the Centre for Disability in Development, in collaboration with Gono Unnayan Kendra (GUK), and with the support of Christian Blind Mission (CBM), has implemented a pilot project on Disability-inclusive Disaster Risk Reduction (DiDRR). The project focused on the inclusion of persons with disabilities and their families in disaster management and resulted in learning and good practices that can be adopted by disaster management professionals, not only in Bangladesh but in the whole region (DiDRR, 2011).

As already mentioned, the Haiti earthquake in January 2010 has posed particular attention to the critical conditions of persons with disabilities in emergency. A toolkit, *"Haiti: Reconstruction for All"*, was developed by the Working Group on Haiti of the Global Partnership for Disability and Development. The toolkit offers *"to development stakeholders, United Nations entities, governments and other organizations involved some useful and proactive planning strategies and tools, which address the needs of persons with disabilities so that all rebuilt and newly built infrastructure is fully accessible to and usable by persons with disabilities and other vulnerable populations"* (Rouhban, 2014, p. 82).

In Pakistan, the large-scale floods during the summer of 2010 affected many persons with disabilities and older people and, therefore, a special task force on disability and ageing made it mandatory for all stakeholders to pose attention to persons with disabilities and to develop inclusive projects. With the same purpose, following the Kashmir earthquake in 2005, a project was carried out to *"both enhance direct service provision to persons with disabilities as well as mainstream disability concerns into the development activities of agencies working on recovery and reconstruction*" (World Bank, 2006).

Smith et al. (2015, p. 8) reported that in India, *"the development NGO Sanghamam recruited persons with disabilities as part of their implementing teams, which has raised the status of persons with disabilities in their communities"*. International NGO *Action Aid* was also noted for its efforts in India investing 10% of all relief resources available to persons with disabilities on the implementation of inclusive training and

capacity building materials (Kett et al., 2005). Also the Social Education for Development - a partner of *Action Aid* - was noted for its community based rehabilitation (CBR) programme. More in detail, it worked with the government to implement education, livelihood and awareness training for people with disabilities, although it was not clear if this was addressed only for persons with disabilities or the whole community (IDRM, 2005).

1.3 International Legislative Framework

In the context of disaster risk reduction, it is crucial to introduce two essential concepts: *coping capacity* and *resilience*. UNISDR (2009) defined coping capacity as *"the combination of all the strengths, attributes and resources available within a community, society or organization that can be used to achieve agreed goals. Capacity may include infrastructure and physical means, institutions, societal coping abilities, as well as human knowledge, skills and collective attributes such as social relationships, leadership and management"*. In general, such capacities involve management of resources before, during, and after the disaster (Villagrán De León, 2006; ISDR, 2002). The concept of coping capacity is strongly linked with idea of resilient communities. In fact social resilience is the ability of a community to face internal or external crises and effectively resolve them. In the best cases it may allow groups to not simply resolve crises but also learn from and be strengthened by them. It implies an ability to cohere as a community and to solve problems together in spite of differences within the community (WRI, UNDP, UNEP & World Bank, 2008).

Many international agreements and treaties have recognized the importance of disaster risk reduction with respect to individuals with disabilities. For example, Article 32 of the UN Convention on the Rights of Persons with Disabilities (CRPD) recognizes that international programs should be inclusive and accessible to people with disabilities. Article 11 of the Convention declares that States Parties: *"shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters"* (CRPD, 2006). Crock *et al*. (2014, p. 10) explained how the CRPD operates as *"something of a game-changer in the field of international humanitarian law (IHL)*". The authors also argued that the CRPD highly contributed to expand the way persons with disabilities are protected and they concluded that article 11 of the Convention is a *"unique provision that establishes a more robust forum for hearing complaints by victims of armed conflict - and natural disasters – than any other human rights treaty"*. In concurrence with Article 11 of the CRPD, the Verona Charter on the Rescue of Persons with disabilities in Case of Disasters (European Emergency Number Association, 2007) lays out foundations for ensuring the protection of persons with disabilities. In 2011, *"the Sphere Project was*

developed in order to improve international response to disasters. The project recognizes disability as a cross-cutting theme across all sectors of disaster response"(Stough and Kang, 2015, p.141).

In the context of ongoing discussions on the post-2015 UN development agenda, United Nations entities are making significant efforts to ensure that a resultant framework is inclusive of disability-related issues. *"The United Nations General Assembly, through its resolutions 63/150, 64/131 and 65/186, defining disability as a cross-cutting development issue, has stressed the urgent need to include a disability perspective and persons with disabilities in all aspects of the global development agenda, including the Millennium Development Goals (MDGs)"* (Ito, 2014, p. 21). Another example of effort to disseminate information and exchange ideas to promote the inclusion of persons with disabilities in disaster risk reduction is the United Nations Expert Group Meeting (EGM) organized by UNDESA, in close collaboration with the United Nations Information Center in Tokyo and the Nippon Foundation. The meeting was held in Tokyo, under the theme *"Building Inclusive Society and Development through Promoting Accessibility in Information and Communication and Technologies (ICTs)"*. It included a special plenary session on the important role played by accessible ICTs in situations of emergency (Ito, 2014).

According to Stough and Kang (2015), the inclusion of disability-related issues in the 2015 UN World Conference on Disaster Risk Reduction (WCDRR) in Sendai, Japan, is the result of a long process, which was developed through the preceding two World conferences: the 1994 WCDRR in Yokohama, Japan Yokohama (Strategy and Plan of Action for a Safer World: Guidelines for Natural Disaster Prevention, Preparedness and Mitigation, UN 1994) and the 2005 WCDRR in Hyogo, Japan (Hyogo Framework for Action 2005-2015: Building the Resilience of Nations and Communities to Disasters (HFA), UNISDR 2005). The Yokohama Strategy did refer to vulnerability, but never with reference to particular populations of individuals. Likewise, people with disabilities were not specifically mentioned as a vulnerable group, nor the experience of people with disabilities with hazards were mentioned in the HFA. The theme of inclusion was covered, but only in the context of education, training and gendered perspectives. In 2014, between the first and the second Preparatory Committee meetings for the Third WCDRR, a Disability Caucus, constituted by six disability advocacy and stakeholder groups, was organized. The Disability Caucus, recognizing that persons with disabilities have remained largely invisible within member states' disaster risk reduction (DRR) policies and practices under the HFA" (UNISDR 2014a), suggested the introduction of direct and indirect references to people with disabilities and disability-related principles (such as accessibility and universal design) in the Pre-Zero Draft of the

Conference. Therefore, three different references to people with disabilities were included in the Pre-Zero Draft released in August 2014. The Disability Caucus highly recommended to consider persons with disabilities not only as recipients of assistance, but as contributors to DRR efforts on accessibility and inclusion (UNISDR 2014b). These recommendations were subsequently reflected in the final version of the Zero Draft, which, in fact, contained five direct references to people with disabilities and indirect references to disability-related principles. Many pivotal themes, commonly used in the field of disability studies and among policymakers, have been included in the SFDRR and the WCDRR, such as (1) *universal design principle; (2) "all of society" approach; (3) accessible technology and communications; (4) the role of individuals with disabilities and disability advocacy organizations.* FEMA (2015) stressed that the WCDRR, meaningfully addressed the invisibility of disability in current approaches to disaster management and incorporated recommendations useful to create a disability-inclusive disaster risk reduction framework. In order to allow participants and speakers with disabilities to access the Conference sessions, closed captioning in English and Japanese were provided and sign language interpretation was available on demand. Furthermore, *"venues provided wheelchair accessible transportation and documents were available in accessible format and blind participants were provided machines that displayed documents in Braille"* (Stough and Kang, 2015, p.141). More than 200 persons with disabilities actively participated in the WCDRR proceedings as either delegates, speakers, panelists, or contributors and thirty-four events addressed various disability-related issues (Stough and Kang, 2015). People with disabilities presented their own expertise in Disaster Risk Reduction (DRR) as part of the working session *"Proactive Participation of Persons with Disabilities in Inclusive Disaster Risk Reduction for All"*. Disability advocates spoke at several sessions, including a public forum entitled *"Taking Action Toward a Disability- Inclusive Disaster Risk Reduction (DiDRR) Framework and Its Implementation"* (FEMA 2015). Finally, according to Stough & Kang (2015, p. 143), *"the inclusion of disability issue in the Sendai Framework for Disaster Risk Reduction 2015-2030 (SFDRR) firmly establishes people with disabilities and their advocacy organizations as legitimate stakeholders in the design and implementation of international disaster risk reduction policies"*. Including disability needs in the SFDRR was an impressive movement forward in advancing international recognition of human rights for people with disabilities. In order to keeping this momentum, persons with disabilities and their organizations must continue to advocate for equal rights in the international arena.

1.3.1 US legislative Framework on Inclusive Emergency Management

The President Barack Obama signed the CRPD on behalf of the United States on July 30, 2009. He transmitted it to the Senate for advice and consent to ratification in May 2012, where it was received and referred to the Committee on Foreign Relations (SFRC) (Congressional Research Service, 2010). The committee reported the Convention favorably to the full Senate on July 31, 2012, by a vote of 13 in favor and 6 against, subject to three reservations, eight understandings and two declarations. On December 4, the full Senate voted against providing advice and consent to ratification of CRPD by a vote of 61 to 38. When the 112th Congress adjourned, the treaty was automatically returned to SFRC. Most recently, on July 28, 2014, SFRC favorably reported CRPD to the full Senate by a vote of 12 in favor and 6 against, subject to three reservations, nine understandings and two declarations. The full Senate did not consider the treaty and therefore, CRPD was automatically returned to SFRC at the end of the 113th Congress (Congressional Research Service, 2010). Generally, issues related to disability rights have received bipartisan agreement in Congress, and there has been support for CRPD among some Senators from both parties. Many policy makers, including those in the Obama Administration, agree that existing U.S. laws are generally in line with CRPD's provisions, and that no U.S. laws or policies would change as a result of U.S. ratification of the Convention. At the same time, other policy makers contended that ratification of CRPD would has adversely affected U.S. sovereignty and interests. During Senate debates on CRPD ratification, a number of issues were discussed and may continue to be points of contention during the 114th Congress (Congressional Research Service, 2010).

According to the International Human Rights Funders Group (2013), the CRPD ratification campaign presents an enormous challenge but also a timely opportunity for significant impact on rights in the United States and throughout the world. According to human rights advocates, ratification could catalyze dramatic inclusion of people with disabilities in U.S. foreign aid and human rights policy and could allow the United States to contribute to advancing international standards on the rights of people with disabilities. Domestically, it would provide a global human rights standard to support U.S. disability advocacy and build upon the civil rights model enshrined in the American with Disabilities Act (ADA, 1990). Ratification will ultimately demonstrate whether the United States holds itself accountable to internationally-recognized human rights standards, not just for people with disabilities, but for any identity group. Focusing on the inclusion of disability in emergency management, although the United States did not ratify the CRPD, *"many federal civil rights laws, including the Rehabilitation Act of 1973 and the*

American with Disabilities Act of 1990, requires equal access for and prohibits discrimination against persons with disabilities during all phases of disaster management" (Roth, 2014, p. 106). More in detail, although the Americans with Disabilities Act (42 U.S.C. §12101 et seq.) does not include provisions specifically discussing its application to disasters, its non-discrimination provisions have been defined applicable to emergency preparedness and responses to disasters by the Department of Justice (Congressional Research Service, 2010). In order to further the ADA's goals, President Bush issued an Executive Order on July 22, 2004 (Executive Order 13347, *"Individuals with Disabilities in Emergency Preparedness*") relating to emergency preparedness for individuals with disabilities and establishing the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (ICC). The Department of Homeland Security (DHS) issued its Nationwide Plan Review Phase 2 Report, which includes a discussion of people with disabilities and emergency planning and readiness. The National Council on Disability has also issued recommendations on emergency preparation and disaster relief relating to individuals with disabilities (Congressional Research Service, 2010).

Since 1979, the Federal Emergency Management Agency (FEMA) has been the United States government's lead agency in responding to emergencies. The Post-Katrina Emergency Management Reform Act of 2006 (PKEMRA) mandates integrating the needs of persons with disabilities into general emergency management and, in fact, one of the FEMA's obligations under PKEMRA was the establishment of a disability coordinator for the agency aimed to ensure that the needs of persons with disabilities are properly addressed in emergency preparedness and relief (Roth, 2014). In 2010, the FEMA Administrator established the Office of Disability Integration and Coordination (ODIC) with the aim to provide guidance, tools, methods and strategies to integrate and coordinate emergency management efforts. ODIC has hosted two conferences: Getting Real, Inclusive Emergency Management National Capacity Building Conference and Getting Real II, Promising Practices for Inclusive Emergency Management. These conferences brought together hundreds of disability community leaders, emergency managers and other key stakeholders to optimize limited resources, improve inclusive emergency management practices and ensure equal services for the whole community (Roth, 2014).

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Chapter 2: Including People with Disabilities in Municipal Emergency Preparedness

2.1. Introduction

Natural disasters are becoming more frequent and affect many groups of people, causing a large number of victims (Barrios, 2014). Among the most vulnerable persons affected by disasters are elderly (Elmore and Brown, 2007; Jenkins *et al.*, 2007) and persons with disabilities (Harris, 2004). Therefore, preparing those persons for disaster should be a priority for all those involved in emergency preparedness and requires *"political commitment, national and local coordination, strategic planning, networking, knowledge management, optimization of resources and the development of good communication strategies"* (Alexander and Sagramola, 2014, p. 9). Emergency preparedness refers to *"actions taken prior to disasters to improve response and recovery efforts"* (Gillespie *et al*., 1993, p. 36) and includes emergency planning, emergency training and supply availability (Smith and Notaro, 2009). The majority of the scientific literature on the issue of disability in emergency preparedness tends to focus on standardized emergency preparedness policies and practices (Smith & Notaro, 2009), rather than on the inclusion of persons with disabilities in the emergency preparedness and decision-making processes. Furthermore, academic research revealed that, in most cases, very few emergency plans have seriously paid attention to the needs of persons with disabilities (Hoffman, 2008). Emergency plans that are inclusive and integrated with the various needs of individuals with disabilities, will work with the general population as well and will improve the ability of the community to respond to an emergency (Roth, 2014). According to Barrios (2014), an inclusive approach should include: (1) raise community awareness of the importance of including persons with disabilities in the emergency preparedness; (2) involving people with disabilities and their families in emergency preparedness process; (3) keep a record of people with disabilities who live in the community and identify what are their specific needs. Furthermore, Alexander and Sagramola (2014) stated that emergency planners should collect adequate and precise information on people with disabilities at municipal level. This may require using census data (in compliance with privacy laws) or conducting a survey of the local area. This information will be useful during emergencies in order to better support and assist persons with disabilities as well as in normal times during the development of emergency plans. Proper emergency planning should also include specific information on long-term care population such as persons living in nursing homes and rehabilitation institutes. *"Such facilities represent, in fact, concentrations of people with a wide range of disabilities and who may require*

specific assistance during an emergency and should not be missed when designing preventative activities" (Alexander and Sagramola, 2014, p. 47). For example, local police and fire stations should have lists of locations where people with disabilities live in concentrated numbers such as long-term care facilities. Lists should to be updated annually and shared with field rescue teams during an emergency. If police and fire departments decide to have registries of people with disabilities, it should be clarified that the registry is an important tool that only helps people who are at home at the time of the disaster without identifying any person with them (DP2-Training Rescue Workers, 2009).

Another important aspect of emergency preparedness is training front-line staff (e.g., first response teams) on disability-related issues. Rowland *et al.* (2007) conducted some interviews with emergency services administrators in three urban and three rural locations in northeast Kansas in order to assess their emergency staff training activities. The study revealed that the emergency management agencies did not have emergency preparedness policies, guidelines or procedures specifically defined to support persons with physical disabilities in situations of emergency. However, most agencies were willing to include people with disabilities in future planning though there was a consistent lack of information on people with disabilities in their areas (Smith and Notaro, 2009). According to Alexander and Sagramola (2014, p. 30), *"simulation exercises are an important extension of both planning and training"* and represent a *"valuable means of testing elements of the emergency response system, highlighting areas that need improvement, and raising awareness of issues"*.

Alexander and Sagramola (2014) stressed the need to give more attention to municipal emergency preparedness because all plans to assist people with disabilities are local in their implementation and outcomes. Rohrmann and Schädler (2013) of the University of Siegen, in order to make the theoretical principle of inclusion usable for implementation, developed the concept of *"inclusive community"* that refers to politically defined local entities such as municipalities or districts. The experience so far has showed that the implementation of the human rights principles is strongly related to the work of municipalities due to their connections with the daily life of citizens and their responsibility for public services (European Association of Service Providers for Persons with Disabilities, 2014). The extent of available resources and staff may differ considerably from one municipalities to another but, in large part, it is the efforts made at national levels that disseminate information and expertise in order to increase the level of emergency preparedness at municipal level (Perry and Lindell, 2003). The intensive debate in many European countries revealed that there is a level of uncertainty in local governments on how to approach and solve disability-related issues in emergency situations (European Association of Service Providers for Persons with Disabilities, 2014). Therefore, more efforts should

be made by stakeholders, political decision makers and other community activists in order to achieve specific political actions (European Association of Service Providers for Persons with Disabilities, 2014)

According to Alexander (2002) emergency planning is an obligation of the civil authorities responsible for the safety and protection of the whole community. Alexander & Sagramola (2014), suggested that, in order to ensure fairness and equity governments must have policies in place that guarantee the basic rights of people with disabilities as well as promote the inclusion of people with disabilities into mainstream society. Local governments should also made efforts to prevent discrimination against people with disabilities and create legal and administrative mechanisms to achieve these goals. It is also crucial to identify exactly which organizations have the responsibility to develop policies in favour of persons with disabilities and to regularly monitor the respect to their ethics, effectiveness and level of implementation. Emergency planning and management may be a jurisdiction of, for example, the Ministry of the Interior (or Home Office). *"In countries (such as Sweden, Italy and the UK) in which emergency responses are a dependency of the national Cabinet, there may be more opportunity to connect the different competencies, but there is no inherent reason why that should occur automatically. Nor does such an arrangement guarantee liaison with outside organizations such as NGOs and voluntary associations, which may be necessary at the operational level in order to provide services for people with disabilities"* (Alexander & Sagramola, 2014, p. 26).
Ideally, government provisions for people with disabilities will be coordinated by a single entity that has a department or unit which is responsible for emergency planning. This agency would need to ensure capillarity throughout the system of public administration, or in other words that arrangements are implemented at the local level and fully backed by local administrations. At this regard, it is crucial to encourage civil protection authorities to cooperate with associations that provide services to people with disabilities (Alexander & Sagramola, 2014).This is one way of connecting two sets of institutions with different competencies and agendas, and also of connecting public administrations with the civil society organizations (Alexander & Sagramola, 2014).

According to the European Commission (2014), the European Union (EU) has competence to carry out activities and conduct a common policy in the area of humanitarian aid. The exercise of this competence is without prejudice to the competence of the Member States in this area. *"Under Article 214, Treaty on the Functioning of the European Union (TFEU), the Union's operations in the field of humanitarian aid are to be conducted in the framework of the principles and objectives of the Union's external action and in compliance with the principles of international law and impartiality, neutrality and non-discrimination. Such operations are intended to provide ad hoc assistance, relief and*

protection for people in third countries who are victims of natural or man-made disasters" (European Commission, 2014, p. 16).

In the field of civil protection, the EU has competences to carry out actions to support, coordinate or supplement Member States' actions. Council Regulation 1257/96/EC concerning humanitarian aid 74 governs the implementation of all EU operations providing humanitarian assistance and states that in responding to humanitarian need, particular vulnerabilities must be considered and that the EU will pay special attention to women, children, the elderly, sick and disabled people, and to accomodating their specific needs (European Commission, 2014). Furthermore, *"the Disability Strategy commits the EU to raising awareness of the CRPD and the needs of people with disabilities, including accessibility, in the area of emergency and humanitarian aid"* (European Commission, 2014, p. 16).The Commission's activities in the field of humanitarian aid are coordinated and conducted mainly through its Directorate-General for Humanitarian Aid and Civil Protection (ECHO). ECHO does not operate directly on the ground, but support through its partners, namely NGOs, UN agencies and international organizations such as the International Committee of the Red Cross and the International Federation of the Red Cross and the Red Crescent Societies (European Commission, 2014). Relations between ECHO and its partners are regulated by framework partnership agreements which determine roles and responsibilities in the implementation of humanitarian operations financed by the EU. *"In the framework of the EU Civil Protection Mechanism, the Commission has co-financed a number of projects aiming at improving the protection of persons with disabilities in disaster situations"* (European Commission, 2014, p. 16).

The System of Civil Protection is composed by a number of authorities, administrations and private and public organizations and parts of the academic community engaged in research into natural or technological hazards within public or private scientific entities or universities. In Italy, prior to 1985, Civil Protection was principally engaged in search and rescue activities and was managed by the Fire Brigade National Corps (Gaetani *et al.*, 2009). In 1992, the National Parliament approved the law no. 225 establishing the National System of Civil Protection (Gaetani *et al.*, 2009). *"In Italy, emergencies are managed at both central level and at the periphery of the system. Such synergy is possible thanks to a network of fully operational decisional-support offices called "Centri Funzionali", in which experts, operating from a network of "situation rooms" all over the country, continuously exchange 24/7/365 prediction data, observational data and evaluations on the evolution of potential disaster scenarios"* (Gaetani *et al.*, 2009, p.16).

As already mentioned, civil protection authorities from national to municipal level are responsible for civil protection planning. For example, at the lowest level, that is the municipal one, the mayor is responsible for developing and keeping updated a municipal civil protection plan covering the response to all possible emergencies (European Commission- Humanitarian Aid & Civil Protection, nd). In that activity, the Department of Civil Protection plays a role of guidance, standardization and control and, specifically the Department is responsible for setting up, maintaining and updating specific national plans. Regions as well as provinces and municipalities must then prepare their civil protection plans according to the directives and guidelines included in national plans (European Commission-Humanitarian Aid & Civil Protection, nd).

More in detail, in Italy, civil protection planning is carried out according to the *"Augustus"* method established in 1997 to face complex emergencies through a standardized and easy-to-implement approach. This method is currently employed as a guideline to set up emergency coordination centres at all civil protection levels and it requires the setting up of up to 14 (regional and national) *"support functions",* which can be organized on a flexible basis:

(1) Planning and technique;

(2) Health, social and veterinary assistance;

(3) Media and information;

(4) Volunteers;

(5) Means and materials;

(6) Transportation and viability;

(7) Telecommunications;

(8) Essential services;

(9) Damage assessment;

(10) Operative structures;

(11) Local authorities;

(12) Dangerous materials;

(13) Assistance to the population;

(14) Coordination of operational centres.

Although, Italy has ratified all main agreements in the field of Humanitarian International rights, only a very few regulations consider people with disabilities. Nevertheless, a document issued by the Ministry of Internal Affairs, elaborated by the Department of Fire Brigade, Public Safety and Civil Defence, entitled "*Aid to disabled persons: indications for emergencies management"*, stresses the importance to ensure adequate support and assistance to persons with disabilities (Office of the High Commissioner on Human Rights, n.d.). This document describes how to cope with different types of disabilities when planning and preparing to respond to an emergency. In particular, the document includes some measures to be adopted to better assist and support persons with disabilities. Even the guidelines for emergency management adopted by the Italian Civil Protection (the so-called *"Augustus method",* regulated by law no. 255/92), stresses that *"particular attention shall be paid to people with reduced mobility: elderly people, disabled, children"* (Office of the High Commissioner on Human Rights, n.d.). It has to be note that, in Italy, fires are the most addressed risk scenario by national legislation. In particular, Ministerial Decree of March 10, 1998 and the circular letter no. 4 of 2002 describe the forms of assistance to persons with disabilities in case of fire. These documents also stress the obligation for the employer to consider the specific needs of disabled workers in the early design of fire prevention measures and in evacuation procedures (Office of the High Commissioner on Human Rights, n.d.). The aforementioned circular, in particular, paves the way to the "*Guidelines for the evaluation of fire prevention measures in workplaces with disabled workers"*, that are based on some important principles:

- involving people with disabilities in the process of risk assessment and the choice of measures to adopt;
- reaching adequate security standards for all, without discrimination;
- elaborating security plans for disabled workers on a holistic basis, that is, avoiding special or separated plans (Office of the High Commissioner on Human Rights, n.d.).

It should be pointed out that Ministerial Decree of June 26, 1992, *"Norms for the prevention of fires for school building"* establishes that each school must have an emergency plan. Furthermore, explicit reference to disability can be found in the *"School emergency plan"* adopted pursuant to Ministerial Decree of March 10, 1998, in relation to emergency and evacuation procedures. It is also important to mention the so-called *"Verona Chart"* concerning the rescue of people with disabilities in case of disasters, drafted after the *"Consensus Conference"*, during which the fundamental principles were stressed for the protection of people with disabilities during emergencies.

2.2 Aim of the Study and Research Questions

It is vitally important to understand the needs of people with disabilities during the exceptional circumstances created by emergency and disasters. Emergency measures should seek to preserve the dignity and (where possible) the autonomy of people with disabilities. Academic and practical studies of disability and disaster reveal that there is a significant shortfall between the recognition of these human rights principles and their implementation in practical programmes of action. The shortfall includes failure to design programmes and plans, implement them and monitor their effectiveness. Planning is an essential part of preparing for emergencies and, therefore, in order to ensure that resources, manpower and organization are in place, plans and preparations need to be made at the national level, which should also be the level at which plans and measures are promoted and harmonized at the intermediate and local levels of public administration. Healthcare institutions, social services, and voluntary organizations in the fields of disability and civil protection need to work together at in both the planning and response modes to create viable programs of emergency care for people with disabilities. Coordination by a single, responsible government entity should nevertheless involve all the organizations involved in responding to emergencies on behalf of people with disabilities. It is important to note that all plans to assist people with disabilities are local in their implementation and outcome, and hence attention needs to be devoted to this level. Emergency plans must be consolidated by frequent updating and testing, which should be complemented by programs of training designed to ensure that all emergency responders are fully familiar with their roles, responsibilities and the procedures they will need to employ in a crisis or disaster (Alexander and Sagramola, 2014). As only few studies have been conducted to explore this area of disaster preparedness, it is not known if individuals with disabilities remain marginalized by local disaster preparedness programs (Rowland et al., 2007). This research study investigates the effectiveness of current municipal disaster preparedness practices as they pertain to include persons with disabilities in decision-making processes. The outcome of this research may provide the impetus for further academic research in this area, potentially leading to improvements in the provision of municipal emergency services to people with disabilities.

The sample population of participants was limited to emergency managers currently employed by municipal administrations. More in detail, interviews were conducted to answer the following research questions:

- Do current municipal emergency plans include strategies for identifying persons with disabilities in the community who may need specific evacuation notification and/or transportation consideration?
- Do the municipalities work closely with healthcare facilities, voluntary organizations or other institutions in order to ensure assistance and support to persons with disabilities in emergency?
- Do the municipalities usually organize public information session, training or exercise to inform the population, including persons with disabilities, about emergency preparedness issues?
- Do the municipalities provide their civil protection personnel with training programs that prepare them to provide for the needs of individuals with disabilities in emergency?

This chapter represent a significant contribution to the municipal emergency preparedness in the Italian context. Specifically the results of the study gave a significant contribution to the development of regional guidelines for a more effective and adequate emergency planning and evacuation procedures for persons with disabilities in Italian municipalities.

2.3 Methods

On May 26, 2014 the International Disability and Development Consortium (IDDC), in collaboration with the Italian Disability and Development Network (RIDS) and the Italian Ministry for Foreign Affairs, launched in Brussels the Italian Disability Development Action Plan, which is one of the first to be adopted amongst EU Member States (Christian Blind Mission, 2014). The action plan is the successful result of an interactive and continuous dialogue among organizations of persons with disabilities (DPOs), government, academic institutions and other stakeholders. The Italian Development Cooperation Disability Action Plan has been recognized as a good example of how to use an inclusive approach to development cooperation. Following the good example from Italy, other EU member states such as Spain, are now also working on establishing a national disability action plan for international cooperation (Christian Blind Mission, 2014). Italy has also distinguished itself for the activities carried out over the time by the National Department of Civil Protection on the issue of disability in situations of emergency. The Department has been engaged, in collaboration with other organizations, in many projects aimed to improve emergency relief efforts for persons with disabilities. Since 2004, the Department and the cooperative society Eucentre are carrying out a research project called "Able to Protect" focusing on the collaboration between persons with disabilities and the Press Office of the Department. The National Department has also organized a seminar, on 9 December 2008, in order to establish a dialogue between civil protection operators and citizens affected by disasters and to develop and share the general criteria for alert and rescue people with disabilities in emergency. A study to verify the presence of procedures and tools for alerting persons with disabilities in emergency was then conducted under the Civil Service of the National Department. The study involved the civil protection at the provincial level, some voluntary associations and persons with disabilities. Moreover, some projects conducted by civil protection voluntary associations in collaboration with regional and local civil protection structures need to be mentioned. The purpose of these projects is to train civil protection operators on disability-related issues in emergency and to include persons with disabilities in the Civil Protection "operating rooms" (VAB Tuscany). Other projects focus on the needs of persons with disabilities in emergency situations such as those conducted by the associations of people with disabilities in the Marche Region (ANIEP Marche in collaboration with EMERGENS) and in Tuscany Region (Comitato unitario handicappati Cecina e Donoratico, AUSER cecina, EFESTO in collaboration with EMERGENS). Finally, many civil protection

practical exercises have been conducted such as the practical exercise organized in the Marche Region in 2010 in which the Council on Disability of the Ancona Province has been involved.

In person interviews have been conducted with the emergency managers of three municipalities in the Marche region (Figure 2.3.1) in order to understand at which extent people with disabilities are involved in municipal emergency preparedness and to define specific guidelines that promote the inclusion of people with disabilities in the emergency preparedness process.

Figure 2.3.1: The selected municipalities in the Marche Region

The interviews lasted about 1 hour. The data used in the qualitative study were gathered in structured in-person interviews examining issues associated with:

- inclusion of people with disabilities in the emergency preparedness process;
- inclusion of disability-related issues in the municipal emergency plan;
- the importance of creating a local network;
- training sessions and practical exercise on disability-related issues.

There was minimal risk to all participants as the study sought self-reported knowledge that was not deemed

sensitive in nature and posed no threat to the individual. The benefit to participation in the study would allow the development of more inclusive and integrated emergency plans. An introduction letter accompanied the interview explaining several things to the participants: the study was described, along with the intended use of the results and it was explained that the study was an academic requirement for a doctoral project. The participation in the study was voluntary and without compensation. Participants might refuse to answer any specific question raised during the interview without giving a reason or explanation for doing so and without any effect on the relationship with the Università Politecnica delle Marche or the other researchers involved. The interviews have been audiotaped. Municipalities names will be used in published articles and reports. Confidentiality in this part of the study was not possible owing to 1) the public nature of the project; and 2) the likelihood that civil protection officials are familiar to each other, known to other officials in government or in the private sector. The voice files and transcripts from the interviews have been archived at the Università Politecnica delle Marche on a secured server and used for educational or research purposes only.

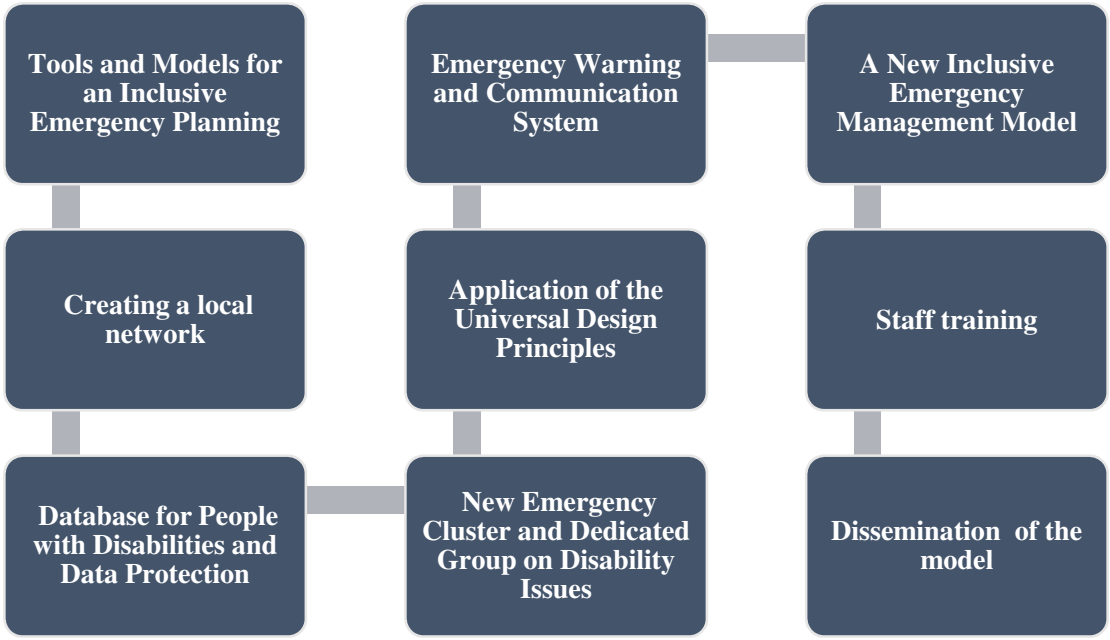
2.4 Results and Discussions

The results of the interviews with the emergency managers of the selected municipalities confirmed the complexity of the disability issue in situations of emergency. One of the major concerns among selected municipalities was the ability to provide an adequate support to the whole community in case of emergency as well as to identify the amount and type of resources that are to be allocated in order to adequately assist people with disabilities. Municipalities clearly stressed the importance, in case of catastrophic events, to improve communication skills of the local emergency response teams. Only one municipality included specific evacuation procedures and transport measures for people with disabilities in the emergency plan. All the municipalities identified evacuation camps and reception facilities but the participants did not specify if these areas and buildings were designed to be usable by all community, according to a universal design approach and in compliance with the Ministerial Decree no 236 of 1989 on architectural barriers free. None of the municipalities reported including systematic data on people with disabilities in the emergency plan. However, participants stressed the importance to collect this information into a regularly updated database in order to improve the effectiveness of evacuation and rescue procedures. All the municipalities provided an on-line version of the emergency plans. However, these plans are not available in alternative formats for persons with disabilities depending on their specific communication needs (e.g., braille, large print, audio and/or video). Only two municipalities specified in the emergency plan which local association is responsible for alerting people with disabilities in case of emergency. However, participants provided few details of how they ensure effective information and communication. There is a lack of networking and collaboration agreements among the selected municipalities and other local authorities and associations. More in detail, only two municipalities reported cooperating with the regional disability advisory council but it was not clear at which extent they discussed disability issues in situations of emergency. Regarding the connection with long-term care facilities, only one municipality explained that the social services have a database with information on the characteristics of such facilities (e.g., types of disability, medical information and specific dietary needs). None of the municipalities included persons with disabilities and their families in the emergency preparedness process. However they all recognized the added value of involving people with disabilities and their representative organisations. As further explained by the participants, the major challenge is to establish a trust relationship with those persons and their families and, at this regard, social services should support municipalities in sensitizing people with disabilities on emergency-related issues and on the importance to share any relavant personal

information with the local emergency mangament agencies. One municipality reported including the International Classification of Functioning, Disability and Health in the emergency plan. However, the main concern beyond the use of the classification was how to develop training sessions addressing the issue of disability in situations of emergency. Another concern was also how to involve persons with disabilities in practical exercises. Again, municipalities stressed the importance of being supported by local authorities and associations in conducting these crucial activities. Municipalities also stressed the need to define guidelines for the development of municipal emergency plans as well as to identify and disseminate standardized emergency and evacuation procedures among municipalities.

The results of the study were used in 2015 by the Department of Civil Protection of the Marche Region to define a set of guidelines intended to develop a participatory and inclusive model to disability in emergency management (Figure 4.3.1) as well as to promote the inclusion of people with disabilities in municipal emergency preparedness. The document also considered the results of the survey conducted in 2011 by the National Department of Civil Protection in collaboration with Europe Consulting Onlus, aimed to understand how Italian municipalities were including disability issues in emergency preparedness. Furthermore, these guidelines aimed to ensure that national and local governments, civil society organizations and relevant offices in both public and private sector have an adequate knowledge of how to proceed with the development of inclusive - disaster risk reduction strategies. The full Italian version of the guidelines is provided in the appendices to chapter 2.

Figure: 4.3.1: New Inclusive Emergency Management Model



Tools and Models for an Inclusive Emergency Planning: the analysis of local civil protection system and existing tools and models (e-tools, GIS tools and Spatial Databases, platforms and apps) available in different national contexts, is useful for emergency planning activities and for the inclusion of people with disabilities in the emergency preparedness process.

Creating a Local Network: it is important to identify all the local authorities and organizations holding data of people with disabilities and to create a local network in order to support civil protection stakeholders. The collaboration of civil protection professionals with healthcare facilities, hospitals, associations of people with disabilities and voluntary organizations is essential in order to provide an adequate support and assistance to people with disabilities in case of emergency. The idea is to collaborate with local facilities and voluntary organizations to identify and assess the needs of people with disabilities and ensure their participation to all the stages of emergency preparedness.

Database for People with Disabilities and Data Protection: Alexander and Sagramola (2014, p.21) stated that *"many countries do not have a register of people with disabilities. This requires that a formal definition of disability be adhered to and people who fall within it be required to register with health and social security authorities, and to maintain a record of their home addresses"*. In normal times, registers serve to determine who receives living allowances from the state as well as to identify needs that health authorities and social services can satisfy. However, registers can also be useful when disaster strikes and during the development of emergency plans, *"as it will represent an inventory of special needs and the location of people who may be in need of assistance"* (Alexander and Sagramola, 2014, p.21). Therefore, it is crucial to create a database with relevant information on people with disabilities and to plan and co-ordinate the rescue activities in case of emergency using the information contained in the database and with the support of GIS technology. The general idea is also to create a map using the information of the database in relation to the more vulnerable areas of the territory. It is also important to ensure the rescue and assistance of people with disabilities safeguarding the data protection. Hence, public administrations must declare in a transparent way and, following the data protection regulation, how they want to use the information contained in the database, worth the offense.

New Emergency Cluster and Dedicated Group on Disability Issues: it is crucial to introduce a new cluster (or a dedicated group on disability issues) within the local emergency management operation centers. This new cluster will be able to organize the rescue services for people with disabilities, in collaboration with local associations of people with disabilities and voluntary organizations. The assumption is that a civil protection staff more sensitive to issues of disability can significantly contribute in making services more accommodating for persons with disabilities. According to

Alexander and Sagramola (2014, p. 22), *"the WHO International Classification of Functioning, Disability and Health (ICF), which is endorsed by many states, endeavours to distinguish between the medical and social approaches to disability. However, it is a complicated tool that has not gained much popularity among people and organisations that work in the disability field"*. Therefore, this task also aims to promote the inclusion of the ICF into the *"emergency management language"* in order to make first responders more confident with disability issues and more aware of the rights and needs of people with disabilities.

Application of the Universal Design Principle: emergency accommodation needs to include accessible amenities such as showers and changing tables for babies. Plans should be made for attendant care and nursing at relief centres for the infirm, people with disabilities and those who acquire impairments. Special dietary requirements and refrigerated storage of medicines need to be catered for, and accessible transport for people with disabilities provided.

Emergency Warning and Communication System: communication and warnings need to be available in multiple formats for people with hearing and vision impairments, low literacy or cognitive processing difficulties, and who do not understand the local language. Auxiliary aids and services, such as pen and paper and sign language interpreters through on-site or video, may be necessary to ensure effective communication. People who are blind, deaf-blind, have low visions, or have cognitive or intellectual disabilities may need large-print information or front-line staff to assist with reading and filling out forms.

A New Inclusive Emergency Management Model: an inclusive model to disability in emergency planning and management should be developed through the coordination of the new cluster and dedicated group on disability issues within the operation centers and the collaboration between the civil protection professionals with the local network (social services, healthcare facilities, hospitals, associations of people with disabilities, voluntary organizations). This new model will include all the strategies for an effective communication system in emergency, the new technologies for search and rescue and the application of decision support systems.

Staff training: first responders, such as search-and-rescue teams, may require additional training or guidance to appropriately assist people with disabilities. They may also benefit from guidance on how to communicate with individuals who are blind, deaf, hard of hearing, or who speak languages other than Italian.

Dissemination of the Model: it is crucial to inform the public about the emergency plan and in particular the measures to assist, rescue and communicate with people with disabilities in an

emergency. Notifications of community meetings should be delivered to the whole community, including those who are housebound.

In conclusion, providing safety and protection for people with disabilities in situations of emergency should be a priority for government policy-makers and emergency management professionals. Following this guidelines would be decisive for a shift from the medical model of disability to the human-rights based approach. In the context of emergency preparedness, looking from this perspective has the benefit of including the needs and voices of persons with disabilities at all stages of the disaster management process and especially during planning and preparedness.

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Chapter 3: A Comparative Study of US and Italian Long-Term Care Facilities - The Value of Inclusive Emergency Preparedness

3.1 Introduction

Nursing homes, skilled nursing facilities and assisted living facilities, (collectively known as long-term care facilities, LTCFs) provide a broad range of health, personal care and supportive services that meet the needs of frail older people and other persons whose capacity for self-care is limited because of a chronic illness, injury, physical, cognitive or mental disability and other health-related conditions (US Department of Health and Human Services - DHHS, 2013). Often, residents of LTCFs must rely on the aid of the staff, drugs and medical equipment on a day-to-day basis (Kendra et al., 2012) and, furthermore, they count on the ability of the facility administrators and the staff to plan, implement and execute appropriate procedures in case of emergency (Office of Inspector General - OIG, 2012). According to Saliba et al. (2004), despite their significant role in serving people with disabilities and older people, LTCFs often are overlooked as a health resource and generally are not incorporated into the community emergency and evacuation plans. Some researchers have dismissed nursing facilities as irrelevant for caring hospitalized patients after a disaster (Pointer et al., 1992) and previous research also revealed that nursing homes received little support from federal, state and local response agencies during and after disasters. (Hyer et al., 2006; OIG, 2006). For example, after Hurricane Andrew in 1992, the general impression was that Florida nursing facilities were not adequately prepared to respond to the emergency (Saliba *et al.*, 2004). Consequently, the Florida Department of Elder Affairs decided to draft a disaster plan template to be followed by long-term care facilities in preparing to face and respond to disaster events (Silverman et al., 1995).

Despite the urgency of the issue, few studies have focused on the ability of nursing facilities to respond to disaster events and, therefore, their role and function in disaster preparedness remains largely undefined (Cron, 2008; Saliba et al., 2004). It was after Hurricane Katrina in 2005 that there has been a growing, but still limited, body of research discussing the experiences of nursing facilities during disaster events (Penta, 2013). In the aftermath of Katrina, the Office of Inspector General (OIG) conducted a study on 20 nursing homes impacted by the storm. The OIG (2006) found that 5 of the 20 administrators interviewed during the study worked beyond the procedures established in their disaster plan, either because the plan did not include instructions for a particular set of circumstances, or

because their plans had not been updated. Then, the OIG suggested 25 emergency plan provisions that, though not required by the Centers for Medicaid & Medicare Services (CMS), under the US Department of Health and Human Services (HHS), would reinforce the emergency preparedness of those facilities. The study, after comparing the disaster plans of the selected facilities to these 25 criteria, revealed many deficiencies in their emergency preparedness such as the lack of guidance for making the decision to evacuate or shelter in place. Furthermore, the emergency plans included limited information about how to handle the specific needs of residents (such as special equipment, medications, level of mobility) and the staff positions and responsibilities for evacuation procedures. The Centers for Medicare & Medicaid Services is part of the Department of Health and Human Services (DHHS) and among other many activities, plays a key role in ensuring continuity of health care services for those persons affected by natural disasters, extreme weather and emergencies. In 2007, CMS provided an emergency preparedness checklist to be performed by healthcare facilities as they develop their emergency plans, actually without requiring them to perform each task. In a recent follow-up study, the (OIG, 2012) compared the emergency plans of 24 selected nursing homes (all certified by CMS, and all affected by disasters) to the CMS checklist. The study found that, on average, the selected facilities included items that corresponded to about half of the checklist-recommended tasks in their emergency plans but more in detail, only 13 of 24 selected facilities were aware of the checklist and only 7 of these 13 used it to develop their emergency plans. The remaining 6 facilities used guidance from other sources, such as their corporate offices or local emergency managers. Furthermore, the OIG (2012) identified some areas in which CMS could add guidance such as searching for missing patients, determining necessary quantities of supplies, revising recommended emergency response measures, tailoring emergency planning templates, and collaborating in healthcare alliances.

In 2004, the National Response Plan (NRP) was created by the National Strategy for Homeland Security; Homeland Security Act of 2002; and Homeland Security Presidential Directive-5 (HSPD-5 - Management of Domestic Incidents, 2003) in order "*to align Federal coordination structures, capabilities and resources into a unified, all-discipline, all-hazards approach to domestic incident management"* (Hyer et al., 2006 p.408; U.S. Department of Homeland Security, 2004). According to the NRP, states and counties are required to have in place an organized disaster response within a unified management structure, which comprise fifteen Emergency Support Functions (ESFs). Specifically, the ESF-8, Health and Medical Services, is responsible during disaster events for *"public health and medical services"*. According to Hyer (2006, p. 408) *"all state ESF-8s recognize hospitals as essential medical facilities, but few accord the same status to LTC facilities*". Also in consequence of this lack in recognizing the prominent role of LTC facilities in healthcare industry, the John A.

Hartford Foundation (JAHF) funded, in February 2006, a long-term care "*Hurricane Summit"* sponsored by the Florida Health Care Association (FHCA). The Hurricane Summit aimed to identify disaster preparedness issues and best practices and to promote the Florida's integration of LTC facilities into the state Emergency Operations Center (EOC) as a model for disaster preparedness at federal, state, and local levels. Hyer (2006, pp. 1962-1963) pointed out five areas for further investigation identified by the Summit participants

(1) including LTCFs representatives into the state EOCs for all phases of emergency management;
(2) establishing decision-making criteria and guidelines for resident evacuation
(3) developing effective communication systems
(4) establishing resident tracking system
(5) developing and refining disaster preparedness guide.

With regard to this last area of discussion, it must be stressed that little is published regarding the experience of LTCFs staff and residents and the importance of their participation to the emergency planning process and practical exercises. Moreover the existing literature focuses almost exclusively on the views of administrators. This is a notable shortcoming, as the health and well-being of LTCFs residents are affected directly by their routine daily interactions with direct care staff. In order to respond adequately to an emergency, a LTCF must rely on the skills, knowledge, commitment, active involvement and compassion of its direct care workers, in addition to preparation at the administrative level (Laditka *et al*., 2009). Regardless the inclusion of residents in the emergency planning of nursing facilities, administrators, medical directors and nurses understand all too well that the acuity of their residents increases the likelihood of injury or death in the event of an emergency. For example, the presence of residents with complex clinical conditions requiring the regular use of oxygen, routine dialysis treatments, or tracheotomy care raises the stakes for emergency planning for LTCFs and the local emergency management system. There may be unique needs related to obese residents requiring special equipment and lift and transfer techniques. Further, many residents may suffer from cognitive disorders causing severe functional disability. Therefore, comprehensive emergency plans should include the clinical condition of the residents served as well as the numbers of residents having certain conditions that will increase their risk of harm during an emergency. But what does really mean including people with disabilities or older persons in emergency planning? In the context of LTCFs the development of strategies for including the resident and their families in the emergency preparedness process may require nursing administrators, nursing staff, residents and their families to work collectively in designing emergency plans and evacuation procedures. According to (Roth,

2014), in order to adequately meet the needs of people with disabilities, emergency managers should understand the concepts of accessibility and non-discrimination and how they apply in emergencies. For example, people who are blind, deaf-blind, have low vision, or have cognitive or intellectual disabilities may need large-print information or healthcare staff to assist with reading the emergency plan (Roth, 2014). Another good attitude is to provide to residents the emergency plan in alternative formats depending on their communication requirements: braille, audio and or CD.

Preparedness activities represent the internal efforts that long-term care facilities must made in order to be better prepared to respond to an emergency. Scientific researchers usually recommend to design and construct emergency plans for nursing facilities and to update those plans in a regular basis because there are many evidences that difficulties are likely to arise with plans that are outdated (Castle, *et al* 2008; DHHS 2006; GAO 2006). In addition, in order to develop a culture of safety that promote the inclusion of healthcare staff and residents in emergency planning, researchers must be sure to collect data also from them. According to Taylor *et al*. (2005), the term *"culture of safety"* is used to describe how the emergency management system of long-term care facilities affects the safety of residents. A study conducted in Hong Kong by Loke and Fung (2014) revealed that *"disaster nursing"* has not yet been established as a core topic to be included in nursing programs. Specifically, the International Council for Nurses (ICN) has suggested that particular attention is required related to planning and preparation, as well as the understanding of the whole disaster management process (Loke and Fung, 2014).

Another aspect of concern is the mental health and stress management of staff (Laditka, et al 2008; Bishop and Thornby 2009). In fact, not only will an emergency affect the residents, but it will inevitably impact the staff caring for those residents as well. Staff too will require unique considerations such as transportation to and from the facility, sleeping arrangements if they will be staying on-site for the duration of the event, and a sustainable rest-to-work ratio as well as other staffers to relieve them. In addition, the ability of staff to employ improvisational skills such as innovation and resourcefulness is reported a crucial element (Boutwell 2002; Augustine and Schoemetter 2005; Johnson 2005). In the Augustine and Schoemetter study of 2005, for example, such skills proved particularly valuable when the Galion Community Hospital in Columbus, Ohio, evacuated because of a credible bomb threat. Soon after the decision to evacuate, the staff secured three impromptu evacuation sites. The authors accredit the fact that there were no mortalities resulting from the event to the innovation and resourcefulness of the staff. This further highlights that all the while, among loss

of supplies, inoperable equipment, logistical difficulties and while managing their own stress, staff still have to provide quality care to the residents. Part of this care will inevitably include the mental and emotional health of the residents as well, and Laditka *et al*. (2009) recommend having nurses and/or social workers on call for such events. However, given that the staff members have daily contact with the patients, they may be the most qualified to, at the very least, monitor the patient‘s mental status. If psychological treatment is necessary, it may be possible for staff to receive training prior to an event on what Brown *et al.* (2009) call “psychological first-aid”. Danna, *et al*. (2009) suggest that clearly defining staff roles and responsibilities prior to an event helps produce better outcomes during the response to and recovery from a disaster. Although not all researchers agree on the importance of providing mental health assistance, Fernandez et al. (2002) argue that the demand for mental health assistance for elderly adults appears to be rather low and resources should instead be allocated to providing economic assistance during recovery. This subject of mental health needs for staff and residents requires further investigation and study.

The scientific literature also stresses the need for practical exercises such as drills and tabletops (Bowers, *et al* 2004; Brown 2007). LTCFs are expected to carry out drills in order to test facility plans and adequacy of staff training. Fire drills are the most common and frequently conducted types of emergency exercises utilized by nursing facilities, but other more complex scenarios are also rehearsed (Brown, Hyer, Polivka-West, 2007). One study explains that staff members who were questioned during the response to an event requested that drills be conducted more frequently (Sebastian, *et al* 2003). All nursing staff should be involved in education meetings, training sessions and practical exercises concerning emergency planning and evacuation procedures. Staff should receive concrete information about their performance during practical exercises and of course they should give their feedback in order to make program improvements. Finally, a strong leadership at the administration level is essential in establishing a culture of safety. The primary role of nursing administrators is to make safety a top priority within the facility and to have clearly defined safety policies. Furthermore, according to Ruder (2012), conducting training drills and education activities to residents, along with the evaluation of their effectiveness, is vital to preparation. It is important to consider the health conditions of the residents before including them in a practical exercise and to address their fears and concerns during and after drills. In fact, in case of emergency drills, some people with disabilities may experience heightened anxiety and may need to be exempt from participating. One-on-one emergency planning with these individuals may be a good alternative. Furthermore, during an emergency drill, it is not necessary for residents with mobility disabilities to evacuate the building completely. In alternative, those residents could be trained separately from general drills in assistance techniques; for

example, how to use an evacuation chair, if one is available, or in transfer and carrying techniques (BC Coalition of People with Disabilities, 2008). However, it is crucial to ensure that residents and their families are aware of and knowledgeable about the facility emergency plan. For example, at least, family members should know how and when they will be notified about evacuation plans and how they can be helpful in an emergency (e.g., if they should come to the facility to assist their relatives) and how/where they can plan to meet their loved ones. Out-of-town family members should have a number they can call for information and residents who are able to participate in evacuation should be aware of their roles and responsibilities in case of emergency (CMS, 2007).

The more recent Hurricanes have posed the attention on the need for improvement in training of administrators, specifically in regards to how they are to make the decision to evacuate (Brown, Hyer, Polivka-West, 2007; OIG, 2006). A study conducted by the US Department of Health and Human Services of 2006 revealed that administrators of 5 of 13 LTCFs that evacuated during Hurricane Katrina described negative impacts on the health conditions of their residents (Office of Inspector General, 2006). At this regard, it is crucial to ensure proper handling of fragile evacuees through specialized staff training, to define guidelines on evacuation procedures and follow them in case of evacuation.

Finally, the importance of building an external network for long-term care facilities is another significant element of emergency preparedness. LTCFs administrators should ensure that more efforts are made to increase not just the internal preparedness of the facility, but its external network as well. Of primary importance is the issue of how local emergency management agencies perceive LTCFs. Many authors claimed that the importance of LTCFs for emergency management is not adequately recognized and then, LTCFs remain neglected as healthcare resources (Brown, Hyer & Polivka-West, 2007). Failure to perceive LTCFs as high priority facilities leaves them in a position where less assistance is offered during the phases of emergency management. The failure to perceive LTCFs as valuable healthcare resources in emergency management may be the reason for the frequent absence of LTCFs in community emergency plans (Laditka et al., 2009). According to a number of LTCFs administrators and staff, there is a lack of connectivity between these facilities and local emergency management agencies (Office of Inspector General, 2006).

3.2 Legal Framework for Emergency Preparedness of Us and Italian Long-Term Care Facilities

Both in the United States and in Italy, the role of LTCFs is relevant. In the United States, largely due to aging baby boomers, the population is expected to become much older, with the number of Americans over age 65 projected to more than double, from 40.2 million in 2010 to 88.5 million in 2050 (US Census Bureau, 2010). An important consideration is that the oldest old population tends to have the highest disability rate and need for long-term care services (U.S. Departement of Health & Human Services, 2013). In fact, although people of all ages may need long-term care services, the risk of needing these services increases with age and recent projections estimate that over two-thirds of individuals who reach age 65 will need long-term care services during their lifetime (Kemper, Komisar, & Alecxih, 2005–2006). According to Chou et al., 2004, the elderly adults in the United States required the most intensive forms of care. Moreover, disasters that affect the elderly often lead to costly and complicated medical, psychological and chronic care needs (Kendra et al., 2012). In the United States the vulnerability of residents of LTCFs became a national issue when thirty-five individuals at one facility perished during Hurricane Katrina in 2005. Under the US National Response Framework, the Department of Homeland Security (DHS) can activate the National Disaster Medical System (NDMS) to respond to incidents, including a presidentially declared major disaster or emergency under the Robert T. Stafford Disaster Relief and Emergency Assistance Act (GAO-06-443R, 2006). However, although NDMS has agreements with non-federal hospitals for patient evacuations, it does not address the specific case of LTCFs (Georgia Accountability Office, 2006). Federal regulations (42 CFR Part 483, Subpart B - Requirements for Long Term Care Facilities; 42 CFR 483.70 - Physical environment) require facilities that receive Medicare or Medicaid payments to maintain and update their emergency plans. These regulations describe several aspects of the facilities operations, such as health care services, dietetic services, and physical environment, including emergency management (GAO-06-826, 2006). State agencies are required to survey and certify facilities in order to ensure that the requirements of the Centers of Medicare and Medicaid Services (CMS) are being meet. According to (FEI Behavioural Health, 2012), when developing an effective emergency response program, most organizations will benefit from specialized guidance for their specific industry. Best practices have demonstrated that the minimum critical elements of an effective disaster program should include (a) *identifying hazards specific to the facility;* (b) *risk assessment specific to the facility;* (c) *developing a robust emergency/disaster plan that addresses how to mitigate, prepare, respond and recover from hazards and risks specific to the facility;* (d) *an employee-wide training program on the disaster response plan;* (e) *drills and exercises to test the disaster plan;* (f)

schedule of regular updates to the disaster plan (FEI Behavioral Health, 2012). In 2007, the Centers for Medicare and Medicaid Services (CMS) published an emergency preparedness checklist as a *"recommended tool"* for healthcare facilities. In addition to the Federal regulatory requirements for nursing facilities emergency response plans, the checklist suggests the development of the emergency, evacuation and shelter-in place plans with an all-hazards approach; the collaboration with local emergency management agencies and with suppliers/vendors that have been identified as part of a community emergency plan; communication contingencies; transportation resources; resident identification; family member notification; necessary provisions; tracking of residents; relocation assistance (CMS, 2007). With regard to the inclusion of residents and their families in the emergency preparedness process, it is important to note that CMS guidelines require facilities to ensure that residents, patients and family members are, at least, aware of and knowledgeable about the facility plan. For example, families know how and when they will be notified about evacuation plans, how they can be helpful in an emergency (example, should they come to the facility to assist?) as well as how and where they can plan to meet their loved ones. In addition, out-of-town family members are given a number they can call for information and residents who are able to participate in their own evacuation are aware of their roles and responsibilities in the event of a disaster.

In Italy, social care and integrated social-health care services are assuming an increasingly prominent role, owing to the rapid growth in demand for long-term care (LTC) services, and more generally, for health care and social services for the elderly, caused by the rapid ageing of the Italian population (Tediosi and Gabriele, 2010). According to the Italian National Institute of Statistics (ISTAT, 2014), the age structure of the Italian population has grown old as the result of the gradual increase in the average life-expectancy, while the decrease in the younger cohorts, sharper in the Center-North, results from the decline in the fertility rate which, starting from mid-70s, has gone down for three decades. According to (European Network of Economic Policy Research Institutes, 2010), the Italian LTC system involves municipalities, local health authorities (*aziende sanitarie locali,* ASLs), nursing homes (*residenze sanitarie assistenziali,* RSAs), the National Institute of Social Security (Istituto Nazionale Previdenza Sociale, INPS) and other players involved in planning and funding these services (e.g., the central state, regions and provinces). More in detail, in Italy there are three different kinds of nursing facilities:

a) *residenze assistenziali* (residential care facilities or assisted living facilities) with mainly hotel services for self-sufficient persons;

b) *residenze protette* (social and healthcare facilities) which help residents recover as much psychomotor capability as possible;

c) *residenze sanitarie assistenziali* (nursing homes or skilled nursing facilities), which provide health care for dependent persons.

The Ministry of Health is the central body of the Italian National Health Service (NHS), which operates at various levels with the obligation to guarantee health care as a fundamental right of the individual. The regions and autonomous provinces plan and organize in their own territory the health services and the activities for health protection, coordinating and monitoring the actions of Local-Health Care Authorities (Aziende Sanitarie Locali, ASL) and Hospitals. The Local Health Care Authorities have the crucial role to assure the delivery of care through public and private accredited facilities such as LTCFs. In case of emergency or disaster, NHS contributes to civil protection through the assessment of the priority measures to be adopted. It also provide, in collaboration with the representatives of the autonomous regions and provinces, all the information available concerning human health, logistics and technological resources available in the area affected by the event (OECD, 2010). More in detail, emergency preparedness of Italian LTCFs is regulated by Legislative Decree no. 81/08. By the end of the 1970s a series of European social directives had been transposed into the Italian regulatory system, which progressively introduced a new approach to the issue of *"safety management"*. This new approach deals with the organization, training, information, awareness and participation of workers and saw its full development with the adoption of the Directive 89/391/EEC of 12 June 1989 *"Improvements in the safety and health of workers at work"*, implemented in Italy with the legislative decree n. 626 of 1994. This was the first instance of a legal obligation to organize company safety policies, and to manage them according to the provisions of Legislative Decree no. 626 of 1994. On 30 April 2008, Legislative Decree no. 81 *"Implementation of Article 1 of the Law of 3 August 2007, no. 123, concerning the protection of health and safety in the workplace"* was issued (European Fund for the Integration of Third-Country Nationals, n.d.).The new Decree coordinated, rearranged and reformed the existing rules and the main cornerstones of the legislation on health and safety in the workplace. In view of the wide scope of Legislative Decree no. 81 of 2008, the organization of policies directed at protecting workplace safety, must be tailored to each situation and take into account the operational guidelines provided by the legislature, particularly in Title I of the Decree. The Legislative Decree no. 81 of 2008 also includes obligations for the employer to provide workers with adequate information and training and specific instructions to follow the emergency plans (European Fund for the Integration of Third-Country Nationals, n.d.). Specifically, the emergency plan should contains (a) actions to be taken and implemented by workers in case of fire; (b) detailed procedures for evacuation; (c) instructions for requesting assistance from the fire response teams and providing them with necessary information upon their arrival; (d) measures to assist people with disabilities. Although there

are no specific guidelines mon how to include residents of LTCFs in the emergency preparedness process, Ministerial Decree of March 10, 1998 and circular letter no. 4 of 2002 describe the forms of assistance to persons with disabilities in case of fire and stress the obligation for the employer to consider the needs of workers with disabilities in the early design of fire prevention measures and in evacuation procedures. The aforementioned circular, in particular, paves the way to the *"Guidelines for the evaluation of fire prevention measures in workplaces with disabled workers"*, that are based on some important principles such as involving people with disabilities in risk assessment process; reaching adequate security standards according to universal design principles and elaborating security plans for disabled workers without discrimination, that is, avoiding special emergency plans (European Fund for the Integration of Third-Country Nationals, n.d.).

3.3 Aim of the Study and Research Questions

The analysis of scientific literature on long-term care facilities (LTCFs) revealed that no specific studies focused on how to include the staff and the residents of those facilities in the emergency preparedness process. Research has also revealed that, in most instances, the emergency plans of those facilities have not seriously considered the needs of their residents. While it is not possible to eliminate all the catastrophic outcomes associated with emergencies, proper and systematic emergency planning would greatly reduce the negative consequences. Every environment in which persons with disabilities reside should have proper measures in place to adequately respond to an emergency The emergency plans should be flexible enough to meet the changing demands of any emergency in which residents find themselves and accessible to all residents according to the principles of equal access and effective communication. As already explained, the residents of long-term care facilities count on administrators and healthcare staff to plan and execute appropriate procedures during emergencies and disasters (OIG, 2006). Therefore, both administrators and the staff of those facilities can play a key role to improve the capacity of the facility to respond to an emergency, to implement the emergency preparedness process, to promote the inclusion of the residents and their families in this process and finally to better assist and support residents in case of disaster. Lack of staff preparedness may include, but is not limited to, insufficient training on emergency preparedness, little involvement in the emergency planning process and low perception of the importance of conducting some activities such as training and practical exercises. The perception of the staff of emergency preparedness needs to be addressed so that the emergency department of long-term care facilities can function more cohesively by identifying areas that need to be improved to respond to an emergency. Therefore, this study also looked at staff perception of emergency preparedness to identify areas of strengths and improvements in emergency planning and response. Finally, the administrators have a leading role in establishing a culture of safety inside of long-term care facilities. The primary role of the administrators is to make an adequate emergency preparedness a top priority within the facility and to have clearly defined safety policies.

The study aims to identify significant differences between the emergency preparedness process and the organizational and safety culture of US and Italian long-term care facilities. Furthermore, the study is a response to the evident gap that exists in academic literature regarding the inclusion of the staff and the residents in the emergency preparedness process.

More in detail, this study focuses on:

1. the level of emergency preparedness of the healthcare staff;

2. training and exercises;
3. evacuation related-issues;
4. the inclusion of residents and their families in the emergency preparedness process;
5. external collaborations with emergency management agencies and first response teams;
6. strengths and areas of improvement.

A series of research questions was defined to better analyze the specific situation inside the facilities:

1. What are the differences in terms of emergency preparedness between US and Italian facilities?
2. What is the current level of involvement of the residents of US and Italian facilities, and their families, in the emergency preparedness process?
3. Currently, are there any US and Italian regulations that oblige the facilities to address the specific needs of the residents in the emergency plan and to involve them in the emergency preparedness process?
4. Do the US and Italian facilities collaborate with local first responders to ensure the development of an integrated emergency plan and to conduct practical exercises?
5. What are the US and Italian facilities' major strengths and areas of improvement in terms of emergency preparedness?

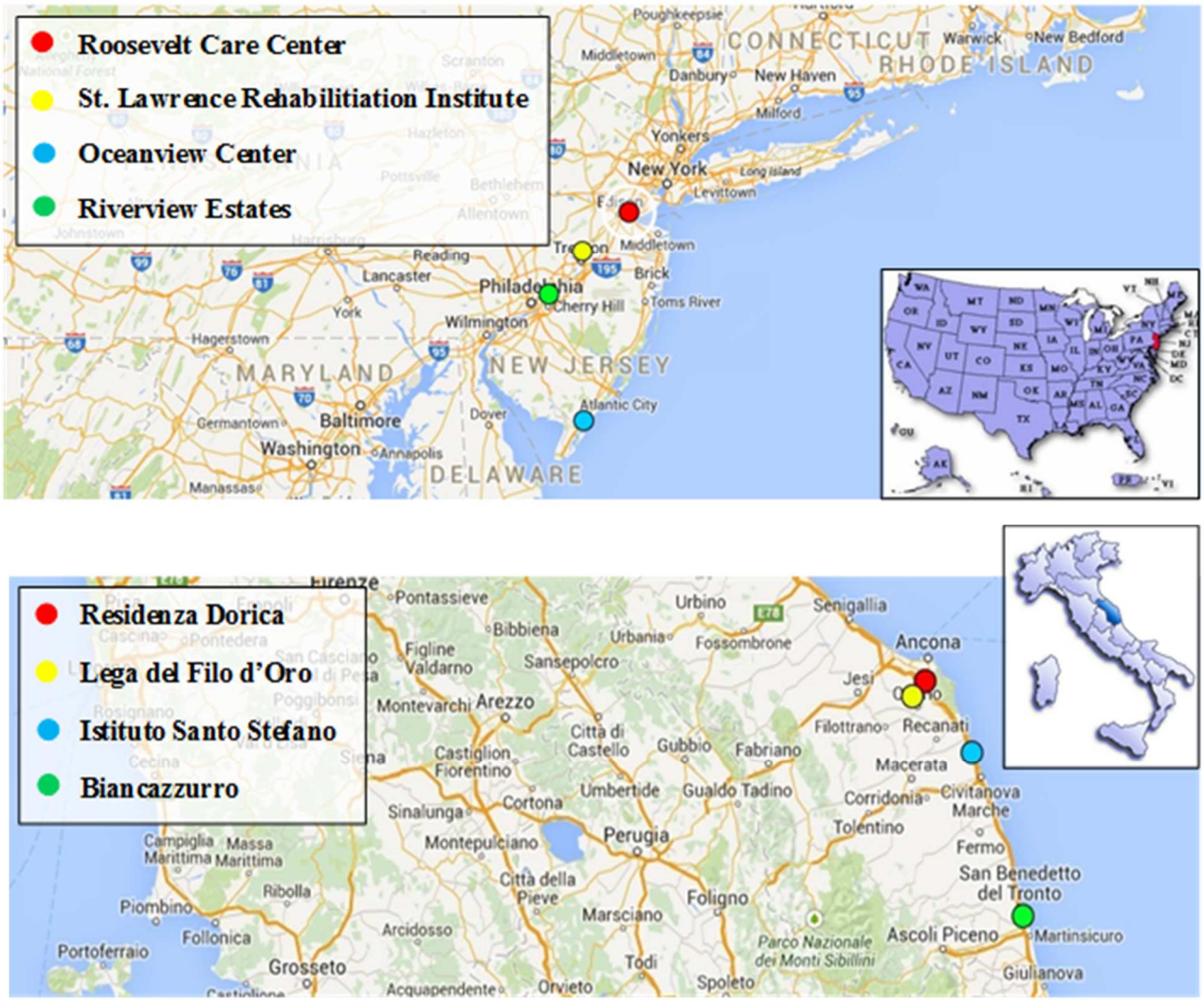
The last part of the study focused on a practical exercise conducted by Lega del Filo d'Oro (LFO), a rehabilitation institute for children and adults with visual, hearing and cognitive disabilities, located in the municipality of Osimo, close to the city of Ancona (the capital of the Marche Region). The main objectives of the simulation exercise were to (1) test the facility emergency plan and the effectiveness of the evacuation procedures; (2) verify the integration between the facility and the municipal emergency and evacuation plan; (3) assess the coordination between the staff of the facility and community first responders.

3.4 Methods

3.4.1 Areas of study

This study stems from the necessity of the Civil Protection Department of the Marche Region (a small region on the East coast of central-east part of Italy) and of the Disaster Research Center (University of Delaware, USA), to investigate how US and Italian long-term care facilities (LTCFs) are dealing with the issue of disability in emergency preparedness. As shown in Figure 3.4.1, a total of 8 facilities have been selected as case studies in the State of New Jersey (USA) and in the Marche Region (Central Italy).

Figure 3.4.1.1: Case studies in New Jersey and Marche Region



The areas of study may be affected by different disastrous events and this fact has been taken into account during the survey preparation. Hurricanes and winter storms as well as earthquakes and snow

emergencies have been considered in New Jersey and in the Marche Region respectively. Fires have been considered for both areas of study.

The inundation from Hurricane Sandy in 2012 significantly affected many long-term care (LTC) facilities in New Jersey, severely reducing or interrupting their functionality and the services provided to the community (FEMA, 2013). Since the September 11 attacks in 2001, there has been an increased awareness throughout New Jersey of the crucial need for effective emergency preparedness (Centers for Medicare & Medicaid Services, 2008). In order to strengthen the emergency preparedness of LTC community, the New Jersey Association of Homes and Services for the Aging (NJAHSA) and the Health Care Association of New Jersey (HCANJ) made numerous efforts to improve collaboration and communication among public health entities, health care providers and emergency management services throughout New Jersey. The two provider associations participate in the New Jersey Healthcare Associations Emergency Preparedness Alliance (NJHAEPA) in order to facilitate discussion among multiple provider associations on emergency preparedness-related issues and to promote communication with the New Jersey Department of Health and Senior Services (DHSS). Furthermore, NJAHSA and HCANJ take part in simulated disaster trainings and emergency planning meetings sponsored by the regional Medical Coordination Centers (MCCs) and the Healthcare Associations Coordination Center (HACC) established by the DHSS. Finally, NJAHSA and HCANJ also have used DHSS grant funds to assist providers with updating and implementing their emergency plans (Centers for Medicare & Medicaid Services, 2008). A critical aspect pointed up by the two provider associations is that emergency management representatives tend to underestimate the needs of LTC providers when discussing emergency preparedness. Further assessments conducted in NJAHSA member communities and the interviews with Office of Emergency Management (OEM) coordinators as well as first responders confirmed that there is a limited awareness within the emergency management community of the diverse needs of LTC population (Centers for Medicare & Medicaid Services, 2008).

With regard to the Italian context, there is little scientific literature published on emergency preparedness and disaster experiences of Italian LTCFs. However, the website of the National Department of Civil Protection (NDPC) provides some important documents and information. A heated debate on the devastating earthquakes around L'Aquila in 2009 is still ongoing. The L'Aquila earthquake made Italy a case study for policy-makers, emergency management experts, academic researchers and international organizations. Sixty thousand buildings were significantly damaged, including the regional hospital San Salvatore and the main trauma center (Casarotti et al., 2009) which, according to the NDPC (2015), were replaced by a field hospital provided by the Marche Regional

Authorities. Among healthcare facilities affected by the earthquake, a nursing home in Montereale has been evacuated and 59 residents were transferred to another similar facility. Furthermore, the Prevention Department of the Local Health Care Authorities was unsafe and unusable and, therefore, it was replaced by two prefabs and a tent (NDPC, 2015). Psycho-social assistance was also provided in the evacuation camps according to the guidelines of *"General criteria for psycho-social assistance to be implemented in catastrophes"* of 13 June 2006. The activities conducted by voluntary civil protection associations aimed to respond to the needs of the population with special attention for the elderly, minors and adults with psychological distress. In parallel, ASL health personnel worked in two areas close to the hospital to provide psychiatric day hospital services as well as other child neuropsychiatric services. A tent was also set up in order to assist psychiatric patients and those with mental disabilities, temporarily replacing the damaged Mental Health Centre in L'Aquila (NDPC, 2015).

3.4.2 Methodological background

A mixed method sampling was used to select the target population: probability sampling (random sampling) for quantitative analysis and purposive sampling (representativeness and comparability sampling) for qualitative analysis. Random sampling was applied since it occurs when each sampling unit in a clearly defined population has an equal chance of being included in the sample (Teddlie and Yu, 2007). Furthermore, since this is a comparative study, representativeness and comparability sampling was applied because it include techniques that are used when the aim of the researcher is to (a) find instances that are representative or typical of a particular type of case on a dimension of interest, and (b) to achieve comparability across different types of cases on a dimension of interest. Finally, although some of the purposive sampling techniques are aimed at creating representative cases, most are aimed at producing comparing and contrasting cases (Teddlie and Yu, 2007). According to Tashakkori and Teddlie (2003, p.713), probability sampling techniques are mainly applied in quantitative studies and involve "*selecting a relatively large number of units from a population, or from specific subgroups (strata) of a population, in a random manner where the probability of inclusion for every member of the population is determinable"*. Probability samples aim to achieve representativeness, which is the degree to which the sample accurately represents the entire population (Teddlie & Yu, 2007, p.77). Conversely, purposive sampling techniques are mainly applied in qualitative studies and can be defined as *"selecting units (e.g., individuals, groups of individuals, institutions) based on specific purposes associated with answering research questions"* (Teddlie &

Yu, 2007, p.77). The researcher's ability to creatively combine these techniques in answering a set of research questions is one of the defining characteristics of Mixed Method approach (Teddlie and Yu, 2007).

The target population of the quantitative study was the staff of the facilities. More in detail, a total of 277 healthcare personnel were surveyed. According to Garbutt et al. (2008), it is important to evaluate also the emergency preparedness of the support staff and not only of the nursing staff. For example the emergency technicians also need to understand emergency preparedness and their role in a disaster (Garbutt et al., 2008). Therefore, physicians, certified nursing assistant, administrative personnel, technicians and other ancillary personnel were all included in the survey. The quantitative study is based on one-page questionnaire distributed during March and May 2014. The questionnaire required nearly 20 minutes to be completed and included three core sections sought to obtain data on their perception of emergency preparedness:

1. the socio-demographic characteristics of the interviewed sample (age, gender, years of employment and area of specialization);
2. the perception of emergency preparedness and training, the importance of these activities and their involvement in the emergency preparedness process;
3. the perception of the value of planning and practical experience for evacuation, reception and provision of care (this set of questions were addressed only to physicians, nurses and Certified Nursing Assistant (CNA) since they are those professionals who have the responsibility to provide health care services to the residents of the facility).

Respondents were asked to provide their level of preparedness according to 5-item Likert scale (1= strongly disagree, 5= strongly agree). Specific statements to be responded included the perception of the usefulness of the emergency plan as practical guidance; the level of training provided by the facility; the frequency and the type of emergency drills conducted; the importance of training to understand how to respond to an emergency; the improvements made by the facilities in the area of emergency preparedness and, finally, the involvement of the staff in the emergency planning process.

The target population of the qualitative study was the administrators of the facilities. A total of 8 administrators were interviewed. The interviews lasted about 1 hour. The data used in the qualitative study were gathered in structured in-person interviews examining issues associated with:

- changes in emergency preparedness;
- inclusion of residents and families in the emergency preparedness;

- evacuation-related issues;
- external network and operations;
- concerns, strengths and areas of improvement

Participation varied with the ability to reach an administrator and the administrator‘s willingness to participate. The selection of the US facilities was supported by the Health Care Association of New Jersey (HCANJ). As a first step, an introduction letter describing the purpose of the study, was sent to the Director of the Emergency Preparedness of HCANJ. Hence, some affiliated facilities were contacted by email asking to participate in the study and four of them accepted. For the distribution of questionnaires it was the administrator of the participating facilities who selected the participants, not the researchers. The administrators have been interviewed in order to understand the decision-making process as well as preparedness activities and perceptions of responsibility as a whole across the LTCFs. In terms of precedents for this approach, Mileti et al. (2002) used a similar approach in their study of culture in businesses affected by the Loma Prieta earthquake. The authors explained that their interviews were conducted with corporate representatives high-up enough in each organization to be aware of policies, yet not so high as to be unfamiliar with operations (Mileti et al. 2002). Interviews and survey scheduling began in February 2014 and took place from March through December 2014.

There was minimal risk to all participants as the study sought self-reported knowledge that was not deemed sensitive in nature and posed no threat to the individual. The benefit to participation in the study would allow the development of educational programs to enhance emergency preparedness of the staff, to promote a more inclusive emergency plans as well as to improve understanding of the differences between the emergency preparedness of US and Italian long-term care facilities. No data were collected until after Institutional Review Board (IRB) approval was obtained.

An introduction letter accompanied both the survey and the interview explaining several things to the targeted population: the study was described, along with the intended use of the results and it was explained that the study was an academic requirement for a doctoral project.

The participation in the study was voluntary and without compensation. Participants had to be 18 years old or older to participate in the study and they might refuse to answer any specific question raised during the survey and the interview without giving a reason or explanation for doing so and without any effect on the relationship with the University of Delaware or the other researchers involved.

Participants to the survey were able to complete the questionnaire in private and so confidentiality was preserved and completed surveys were not shared with other staff members. The interviews have been audiotaped or digitally recorded. Organizational names will be used in published articles and reports.

Confidentiality in this part of the study was not possible owing to 1) the public nature of the project; and 2) the likelihood that officials are familiar to each other, known to other officials in government or in the private sector, and have participated in already-documented activities. The completed questionnaires and the voice files and transcripts from the interviews have been archived at the University of Delaware's Disaster Research Center on a secured server and used for educational or research purposes only.

For the quantitative analysis, specific statistical tests were performed to obtain coherent and replicable results. Data sets were checked to find out which tests were adequate and which research questions could be responded. Since data were not normally distributed, non-parametric tests were selected either to explore relationships among categorical and continuous variables (Spearman's rank-order correlation) or to compare groups (Mann-Whitney *U* test). Qualitative descriptive methods (Content Analysis) have been used for the analysis of the interviews.

According to (Alexander and Sagramola, 2014), practical exercises are crucial to test the emergency plans as well the whole emergency response system, underlining areas for improvement and raising awareness of important issues. They give the opportunity to train emergency responders in assisting and supporting people with disabilities, and identify lacks in the execution of emergency and evacuation procedures. Lessons learned from simulation exercises are valuable information about difficulties that would be encountered in a real emergency and, therefore, debriefing exercises should also be conducted in order to understand how anticipate challenges by designing priori solutions. According to Fanning and Gaba (2007), debriefing exercises may help the participants in relating their training experiences to daily practice. In fact, debriefing is widely considered as the most critical component in simulation-based training (Rall *et al*., 2000). In simulation-based training, the main goal of debriefing is to *"engage participants in reflective critique and discussion regarding their performance during simulation scenarios and how they can improve targeted content and skills"* (Gururaja *et al.*, 2008, p.2)

On October 4, 2014, an earthquake drill was conducted by one of the Italian selected facilities, Lega del Filo d'Oro Rehabilitation Institute. This important activity was the result of a strong collaboration (throughout the 3-years doctoral project) among the facility's administration, the Civil Protection Department of the Marche Region, the local emergency managers and the local first response teams (e.g., fire fighters, red cross, local police etc.). In order to integrate the results of the questionnaires and interviews, the study investigated the results and insights gained from the debriefing exercise. Important aspects emerged during the debriefing meeting were discussed and recommendations for further research on safety and emergency response system of long-term care facilities were provided.

The earthquake simulation scenario was developed using real recorded data of the strongest earthquake shock that struck the city of Ancona (the capital of the Marche region, see figure 3.4.2.1) on June 14, 1972. The shock caused wide-spread panic, some damage, several injuries, and one death. Damage was reported to 150 buildings with intensities reaching VIII on the Mercalli scale toppling roofs and cracking walls (USGS, nd).

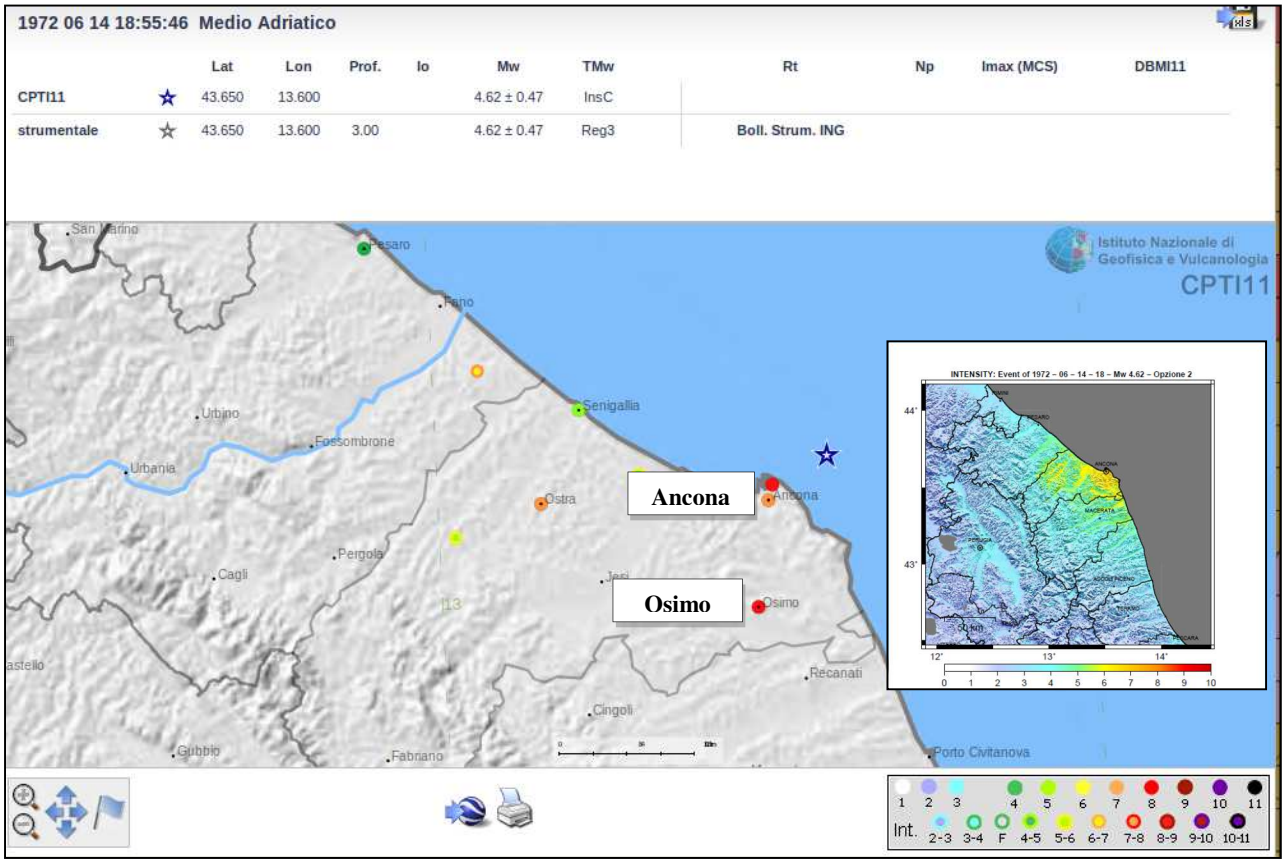
Following are the characteristics of the earthquake shock:

- Epicenter: 43.650 13.600 (few km from the coast in front of Ancona)
- Depth: 3.0 km
- Magnitude: 4.62 ± 0.47

Such an earthquake can also trigger landslides, with obvious implications on road conditions. After a rapid safety evaluation, the administrator of the facility decided to totally evacuate the building. During the evacuation phases, a healthcare worker falls down the stairs, getting a distortion of the lower limb. A total of 35 residents and 65 healthcare workers were involved in the simulation exercise (including some civil service volunteers). In addition, the following experts and professionals were involved:

- Prevention and Protective Service Manager;
- Fire safety team;
- First aid team;
- External safety consultants;
- Department of Civil Protection of the Marche Region;
- Municipality of Osimo (municipal civil protection volunteers, local police, etc.);
- Fire Department of Ancona Province and Municipal Fire Department;
- 118 Operations Center of Ancona and the Regional Health Authority (Area vasta 2 ASUR Marche);
- Local Red Cross unit;
- 2 observers

Figure 3.4.2.1: The earthquake shock on June 14, 1972



Source: Istituto Nazionale di Geofisica e Vulcanologia (nd)

3.5 Results

3.5.1 Survey to the US and Italian staff

A total of 277 healthcare workers answered the questionnaires, 36% US staff and 64% Italian staff. The surveyed personnel in Italy consists of 19% man and 81% women with age from 18 to 68 years old. Five age groups were defined: 18-30 years old; 31-40; 41-50; 51-60; >60 senior personnel. Among Italian respondents 5% were physicians, 55% nurses, 30% certified nursing assistants (CNA) and 10% were classified as other (administrative personnel, kitchen workers, transport workers, technicians). With regard to the years of employment, 30% of respondents have been working in the facility for less than 1 year, 29% for 1-10 years, 25% for 11-20 years, 13% for 21-30 and 2% for 31-40 years. The surveyed personnel in the US consists of 15% man and 85% women with age from 18 to 74 years old. Five age groups were defined: 18-30 years old; 31-40; 41-50; 51-60; >60 senior personnel. Among US respondents 23% were physicians, 23% nurses, 9% certified nursing assistants (CNA) and 45% were classified as other (administrative personnel, environmental health officers, security services staff, kitchen workers, communication officers, materials managers, transport workers, technicians). With regard to the years of employment, 3% of respondents have been working in the facility for less than 1 year, 51% for 1-10 years, 19% for 11-20 years, 22% for 21-30 and 5% for 31-40 years. The socio-demographic characteristics of the interviewed sample are shown in Table 3.5.1.1.

Table 3.5.1.1: Description of surveyed staff

	Age		**Gender**		**Area of specialization**		**Years of employment**	
USA	18-30	15%	Male	15%	Physicians	23%	<1 year	3%
	31-40	9%	Female	85%	Nurses	23%	1-10	51%
	41-50	26%			CNA	9%	11-20	19%
	51-60	35%			Other	45%	21-30	22%
	>60	16%					31-40	5%
ITALY	18-30	24%	Male	19%	Physicians	5%	<1 year	30%
	31-40	26%	Female	81%	Nurses	55%	1-10	29%
	41-50	33%			CNA	30%	11-20	25%
	51-60	15%			Other	10%	21-30	13%
	>60	1%					31-40	2%

Table 3.5.1.2 summarizes data about how the Italian and US staff perceive their level of emergency preparedness and training, the importance of these activities and their level of involvement in emergency planning.

A frequency analysis of the first group of questions shows that there is a drift toward affirmative answers in the US facilities (agree and strongly agree). Some 53% of Italian staff believes that the emergency plan gives a practical guidance on managing emergency, 19% are uncertain about the efficiency of the plan and 11% thinks that the emergency plan is not enough efficient in case of emergency. Among US staff, higher percentage (53% agree and 44% strongly agree) believes that the emergency plan is useful during the emergency operations. Some 53% of the Italian respondents feels adequately trained to respond to an emergency, 20% does not feel sufficiently trained and 17% is uncertain about their level of training. Conversely, US respondents feels more trained to respond to an emergency (61% agree and 34% strongly agree).

Fire drills are conducted more frequently in the US facilities: 53% of the Italian staff states to run fire drills annually and 44% states that they never even participated to a fire drill. Besides, in the US facilities, staff usually runs through fire drills quarterly (20%) and monthly (68%). Other type of drills (earthquake/snow emergency in Italy; hurricane/winter storm in the USA) are also conducted less frequently in Italian facilities (76% never and 23% annually) compared to the US facilities (11% quarterly, 54% annually and 35% never).

Both Italian and US respondents believe that their facilities is improving the way staff is prepared for an emergency and, probably as a consequence of this improvement, a higher percentage of respondents also believe that the basic and continuing training can help the staff to better understand how to face and respond to an emergency. However, despite the improved emergency preparedness programs, Italian staff feel less involved in the emergency planning activities (19% disagree, 19% uncertain and 49% agree) compared to the US staff (55% agree and 31% strongly agree).

Table 3.5.1.2*:* Differences between Italian and US staff preparedness

Questions	Answers	Valid Percent	
		USA	ITA
Our emergency plan gives practical guidance on managing emergency	Strongly Disagree	1%	**/**
	Disagree	1%	**11%**
	Uncertain	1%	**19%**
	Agree	**53%**	**57%**
	Strongly Agree	**44%**	14%
I receive sufficient training to respond to an emergency	Strongly Disagree	1%	2%
	Disagree	3%	**20%**
	Uncertain	1%	**17%**
	Agree	**61%**	**53%**
	Strongly Agree	**34%**	9%
How often do you run through fire drills?	Never	6%	**44%**
	Annually	6%	**53%**
	Quarterly	**20%**	3%
	Monthly	**68%**	1%
How often do you run through other drills? (earthquake, snow emergency, hurricane, winter storm)	Never	**35%**	**76%**
	Annually	**54%**	**23%**
	Quarterly	**11%**	**/**
	Monthly	1%	1%

Basic and continuing training improves understanding emergency response	**Strongly Disagree**	**1%**	**1%**
	Disagree	**/**	1%
	Uncertain	2%	1%
	Agree	**44%**	**58%**
	Strongly Agree	**53%**	**40%**
My facility is improving the way staff is prepared for an emergency	Strongly Disagree	2%	1%
	Disagree	**/**	9%
	Uncertain	5%	12%
	Agree	**59%**	**67%**
	Strongly Agree	**34%**	11%
I feel involved in the emergency planning activities	Strongly Disagree	0%	4%
	Disagree	0%	**19%**
	Uncertain	2%	**19%**
	Agree	44%	**49%**
	Strongly Agree	55%	9%

Table 3.5.1.3 summarizes data about the value of planning and practical experience for evacuation, reception and provision of care. Only physicians, nurses and Certified Nursing Assistant (CNA) were asked to respond to the questions since they are those professionals who have the responsibility to provide health care services to the residents of the facility.

Questions	**Answers**	**Valid Percent**	
		USA	**ITA**
Planning is critical for evacuation, reception and provision of care to residents	Strongly Disagree	/	1%
	Disagree	/	/
	Uncertain	/	1%
	Agree	**22%**	**64%**
	Strongly Agree	**78%**	**34%**
Practical experience in providing care in emergency help me to facilitate care to residents	Strongly Disagree	2%	1%
	Disagree	2%	/
	Uncertain	10%	/
	Agree	**55%**	**54%**

	Strongly Agree	**31%**	**45%**

Table 3.5.1.3: Differences between Italian and US staff preparedness

The frequency analysis of the last two questions shows that more than 50% of the Italian and US healthcare personnel believes that planning is critical for evacuation, reception and provision of care to residents and, furthermore, training is useful to understand how efficiently assist residents during an emergency.

The Mann-Whitney *U* test has been applied to understand if there are significant differences between Italian and US staff. The test verified that US staff have more confidence in the emergency plan compared to Italian staff ($U = 4870.0$, $p < 0.001$, $r = -0.4$) and this is can be related to the fact that US staff also feel more adequately trained ($U = 4753.0$, $p < 0.001$, $r = -0.42$; *Figure a and b*). Moreover in the US facilities fire drills are conducted more frequently ($U = 1196.0$, $p < 0.001$, $r = -0.75$) as well as other type of drills ($U = 3349.5$, $p < 0.001$, $r = -0.43$, *Figure c and d*). The value of Cronsbach's alfa ($\alpha = 0.78$) shows a good internal consistency. The *U* test also reveal that US staff feel more involved in the emergency planning activities carried out by the facilities ($U = 5156.5$, $p < 0.001$, $r = -0.36$) and, furthermore, the US staff perceive a greater improvement of the emergency planning of their facilities compared to the Italian staff ($U = 5975.0$, $p<0.001$, $r = -0.31$; *Figure e and f*).

Fig. a: Efficiency of the emergency plan

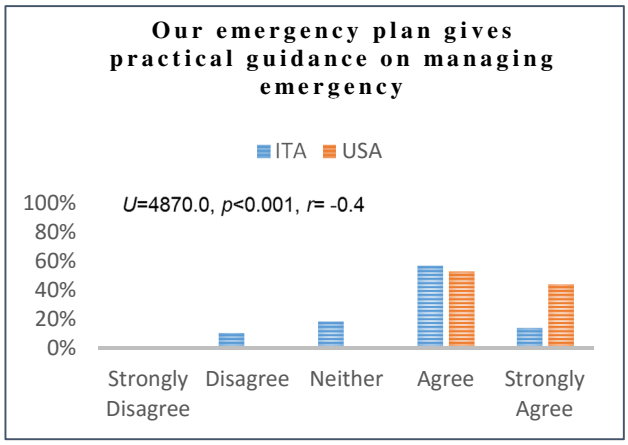


Fig. b: Level of training

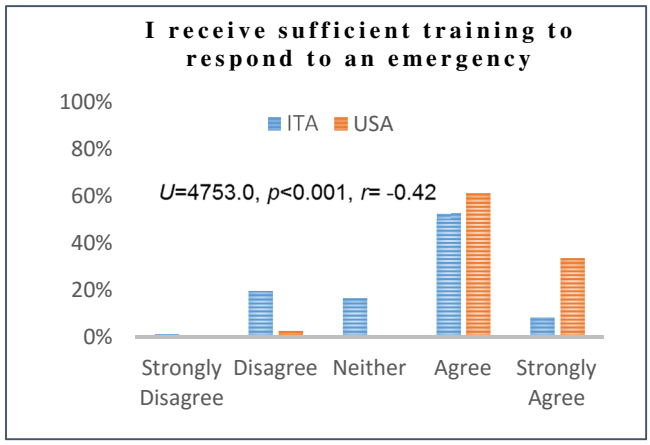


Fig. c: Frequency of fire drills

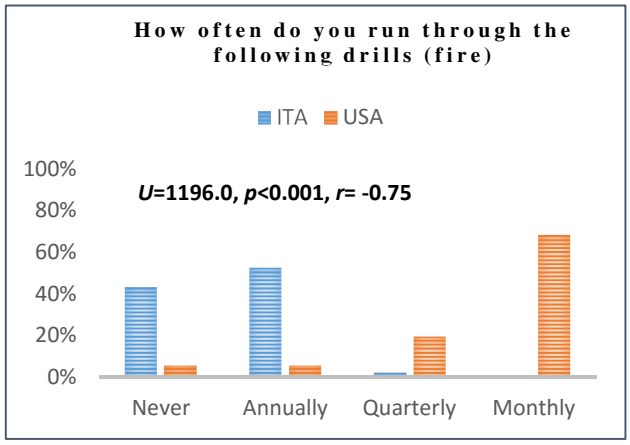


Fig. d: Frequency of other type of drills

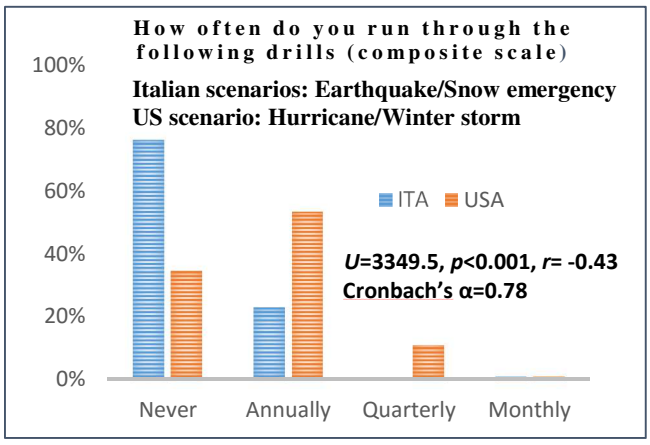


Fig. e: Improvement of preparedness

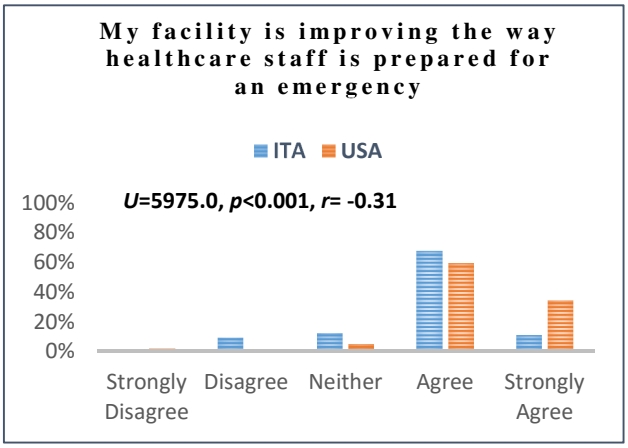


Fig. f: Level of involvement of the staff

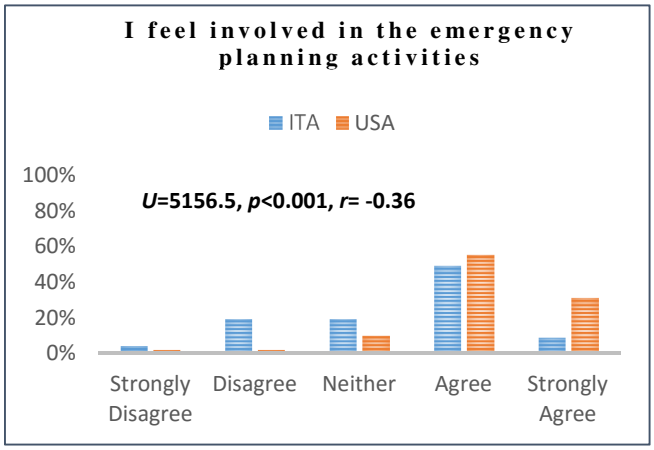


Table 3.5.1.4: Involvement, training and readiness of Italian and US staff

	I receive sufficient training to respond to an emergency		***My facility is improving the way staff is prepared for an emergency***	
	Correlation Coefficient ρs		**Correlation Coefficient ρs**	
I feel involved in the emergency planning activities of my facility	**USA**	**ITA**	**USA**	**ITA**
	0.705**	**0.685****	**0.705****	**0.598****

**** Correlation is significant at the 0.001 level**

- 1.96 < Zobs < 1.96 (Correlation coefficients not statistically significantly different)

Finally, Spearman's rank order correlation has been applied to explore statistical correlation among categorical variables. The test reveals that the more the US and Italian staff consider themselves involved in the emergency planning, the more they feel trained and prepared to respond to an emergency (Table 1.4). This result is a key aspect that confirm and reinforce the importance of involving the staff in the emergency preparedness process of the facility.

3.5.2 Interviews to the US and Italian administrators

Emergency preparedness: planning, training and exercises

US facilities

All the participating facilities mentioned having some kind of planning in place at the time of the interview and recognized the importance to develop a comprehensive Emergency Operations Plan (EOP) to guide the facility in its emergency response. More in detail, the interviewed administrators expressed their awareness of the importance of the EOP to define (a) staff roles and responsibilities that will facilitate effective action during an emergency; (b) to outline contingency plans for communication pathways within the hospital and to the emergency management services; (c) to assess the availability of materials and supplies within the facility and the procurement of assets from vendors

and the community; (d) to secure the safety of the facility, staff and patients; (e) to utilize staff resource to ensure the clinical needs of the patients are met during extreme conditions; (f) to integrate emergency procedures and coordination of operations with those of the Community Emergency Management programs. All of the facilities developed an All Hazards Emergency Preparedness and Response. Therefore, the emergency contact list contained in the emergency plan is comprehensive and includes community first responders for any type of emergency. It also includes certain facility staff, emergency repair vendors and community based agencies, groups and organizations. However, the detail and depth of those plans and as well as the knowledge of the plans, varied across the facilities. Three of the participating facilities have an emergency plan specific to any single type of event such as fires, hurricanes, flooding, utility failure, medical emergency, bomb threat, agitated or combative individual, elopement, hazardous material exposure, persons with gun/weapon, internal or external disasters. Only one emergency plan included specific procedures on transporting medical information (e.g., information regarding the evacuation needs to be provided so medications can be delivered to the correct locations). All the facilities included evacuation plans and they were specific to any single type of event.

Whereas the participating facilities belonged to the Health Care Association of New Jersey and therefore, are included in a larger network of long-term care facilities, the plan was mainly derived from a template provided by the corporate office. In most cases, these templates were then adjusted by the individual facility to reflect the risks and needs as they pertained to their residents and their location. All the facilities are required to review and update their emergency plan on a yearly basis and to submit it to the emergency management county official and the fire office that review and approve the plan. Only one facility reported reviewing (and updating) the plan many times during the year if necessary and generally anytime new issues or concerns come to light such as changing vendors or severe weather notification provided by the state early warning alert service. Another facility also stressed that, over the last three years, the collaboration with the Director of Emergency Preparedness for the Health Care Association of New Jersey has improved. This fact allowed the facility to stay abreast of any changes or conditions that the facility needs to know in order to implement the emergency plan and to take preventive measures to avoid mishaps during potential disaster events. Two facilities explained that after Hurricane Katrina and even more after Hurricane Sandy that, actually impacted their areas, much more attention was given to the extreme events and, specifically, how to track changes in the weather through time. For example, one of the two mentioned facilities was worried about storms coming from the Delaware River, which would bring massive flooding.

The administrator of the facility reported that after Hurricane Sandy many people were moved from the coast to Trenton, but Trenton was also flooded and this critical issue made all the staff of the facility more aware of weather hazards and the importance of an adequate emergency preparedness. The same facility also mentioned many cases of communication failure during Hurricane Katrina and explained that, as a result of that event, now the State requires nursing facilities having ham radio on site and licensed radio operators. Also the other facility confirmed that after Hurricane Sandy the state started expecting more from nursing facilities in terms of emergency preparedness and, as evidence of this, facilities are now required to follow the guidelines of the Centers for Medicaid and Medicare Service to develop the emergency plan. Finally, the administrator of another facility said:

> *"Hurricane Irene had a great impact on our facility. We had to evacuate the building. We saw what was in practice and that has changed our philosophy a little bit in terms of emergency preparedness".*

Responsibility for reviewing the emergency plans was specified in three interviews: administrative staff, heads of the different departments, nursing staff, as well as the local fire department and the emergency management county official were involved in the review process. One of the three facilities reported involving also the families of the staff.

With regard to practical exercises, fire drills were among the most frequently referenced exercises mentioned in the interviews. All the facilities usually were conducting fire drills on a monthly basis. Three facilities mentioned doing one or two annual disaster drills including snowstorm, terroristic attack, hazardous material exposure and gas leak drills. None of the facilities mentioned the state regulations on the frequency and the intensity of the exercises. Although tabletop exercises are frequently used within nursing facilities to think through situations that could arise in emergency, only one facility was familiar with this kind of exercise. This facility usually conducted tabletop exercise twice a year in collaboration with the county emergency management office.

All the facilities agreed on the importance of conducting practical exercises. Two facilities administrators recognized the value of involving all the staff, not just medical staff, and volunteer personnel in the exercise and debriefing exercise. The administrator of another facility explained that, from an education standpoint, the staff have been educated to the fact that conducting drills may help to verify the level of preparedness of the staff and their ability to execute the procedures reported in the emergency plan but also the administrative staff to identity lacks on education and training programs provided. All the facilities mentioned some kind of training for their staff. More in detail, one facility focused on the importance of mental preparedness of all those involved in emergency

management but, mostly, of the healthcare staff which is directly responsible for caring the patients during evacuation phases. In general, all the facilities reported no substantial changes in emergency preparedness after Hurricane Katrina but, rather, more frequent updates and reviews of the emergency plans and recurrent training sessions and exercises in collaboration with the local fire department. None of the facilities provided details on full disaster drills they conducted.

Italian facilities

With regard to the value of emergency planning, all the Italian facilities stressed the need to have an emergency plan, to constantly update it and to provide healthcare staff adequate training. One facility scheduled for the beginning of August, a meeting with the local emergency agency (within the municipality) in order to include the facility into the local emergency plan. Another Italian facility has given priority to structural mitigation measures as well more precise procedures related to snow emergency in response to the 2012 big snow emergency occurred in the Marche region. Following that event the emergency plan has been greatly modified and a special focus now is on the collaboration between the facility and the local emergency agencies in terms of transportation system. All the participating facilities mentioned having some kind of planning in place at the time of the interview but the administrators provided few details on the emergency planning process as well as who was involved in the process. In two of the selected facilities the administrators were also in charge of the *"Risk Prevention and Protection Service*". In the other two facilities, the administrators reported relying on an external consultant (the *"Prevention and Protective Service Manager*") for the development of the emergency plan. None of the facilities mentioned significant changes to emergency preparedness after the Legislative Decree no. 81/08, concerning the protection of health and safety in the workplace, entered into force. Only one facility developed the emergency plan using a multi-hazard approach. The plan, including different scenarios such as fire, flood, earthquake and gas leak, has been shared with all the staff during a training session. At the time of the interview, the facility was also scheduling a meeting with the local emergency management office in order to integrate the emergency plan of the facility with the municipal civil protection plan. Another facility mentioned fire, earthquake and landslide scenarios. The other two facilities only mentioned fire as main concern. None of the facilities followed the *"Guidelines for the evaluation of fire prevention measures in workplaces with disabled workers"* (circular no. 4 of 2002) of the National Fire Department.

All the facilities provided some kind of training to their staff. Training sessions were conducted annually, according to national regulations, but administrators did not provided many details on this issue such as how many hours of theory classes are provided as well as the type of staff involved in

these sessions. One facility reported having a fire safety team composed by 25 certified nursing assistants. The first aid care team included certified nurses and it have to attend biyearly refresher training. Moreover, the facility invited all the staff to participate in specific training sessions on patient handling techniques during evacuation in collaboration with the local fire department.

With regard to practical exercises, fire drills were among the most frequently referenced exercises mentioned in the interviews. All the facilities usually were conducting one or two fire drills once a year. Only one facilities conducted an earthquake drill in October 2014. The drill was the result of a strong collaboration between the facility and the local emergency management agencies (municipality, local fire department, department of civil protection of the Marche region, local police and local red cross units). None of the facilities reported having debriefing exercises.

Evacuation-related issues

US facilities

All the respondents overwhelmingly prefer to shelter-in-place than evacuate. As already mentioned, weather information are considered important by senior level administrative or management personnel in making this decision, including the direction of the storm to determine if they are going to experience a direct hit. Beyond the weather, other factors played a role in decision-making such as the structural integrity of the building, the availability of emergency supplies, the utilities' conditions and the clinical conditions of the patients as well as the availability of places where to go. The decision to evacuate is largely made by senior level administrative but also someone from the corporate office, whether a regional emergency manager or owner, is also involved in the decision to evacuate. At another facility, the administrator explained that also the fire department and the county emergency management office can give the order to evacuate depending on the safety conditions of the building.

One facility clearly expressed concern on the skill of the facility during a potential evacuation:

> *".... but in case of a flood or hurricane I am not sure we would be prepared as we would like to be, we always prefer to shelter in place".*

Here the issue is the need of time to adopt all necessary measures to evacuate and overall. In case of partial or total evacuation of the facility, there are two elements of major concerns: ensuring an adequate transport and communication systems and managing staff and residents with panic disorders. At this regard, in 2006, one facility decided to invest some grant money received from the state to purchase supplies for shelter in place and, more in detail, to improve the communication system (ham

radio) and to implement emergency food storage available for staff and residents but not for their family members.

All the participating facilities have some transportation resources available on site. Most reported having a several passenger bus and vehicles capable of transporting some residents who use wheelchairs. However, those transportation resources are limited, and transportation support would be needed if full evacuation and relocation from the facilities was required. One facility specifically mentioned dealing with the challenges of transporting bariatric patients. Participants want to keep residents out of danger, but were also worried about the negative health consequences (e.g., transfer trauma and stress disorder) that could come with evacuation. Some participants mentioned that staff was a concern, but there were others who directly stated that they were not concerned about the performance of their staff and even identified them as a strength.

One facility emphasized the importance of the role played by the staff during evacuation procedures. The staff, in fact, have to make important decision and is responsible for handling and reassuring patients during the evacuation process. Another facility explained that, sometimes the medical staff, after evaluating the medical conditions of the patients, could decide to send them back home rather than keeping them in the facility. However, it was unclear what criteria are used to make the evaluation, other than the health of the patient generally.

All the facilities keep the resident closed medical records and contact information on a server that is backed up daily. At the initiation of the event all hard copy records will be moved to a safe location. In the event of an evacuation, the administrator will determine which records to take. The remaining records will be put in area(s) that are deemed to be the most safe and secure. To protect electronic information, computer(s) have a non-interruptible power supply (UPS) unit that is tied into the emergency generator and uses software that can initiate an orderly shutdown by properly closing files, databases, applications and then the operating system and hardware. The transfer of medical information in the event of an evacuation is handled in a number of ways, but generally, all the participating facilities transfer files with the individual residents, bagged in plastic to protect the paper files.

Italian facilities

All the participating facilities mentioned that the negative health consequences that could come with evacuation is the major concern. Three facilities reported that staff was a concern. Only one administrator was not concerned about the performance of the staff and even identified them as a

strength. All the facilities mentioned the medical conditions of the patients in case of evacuation and the availability of places where to move them (hospitals or other facilities) as the two most significant factors that influence the decision to evacuate or shelter in place. One facility clearly explained that they always prefer to avoid or, at least limiting, patient handling and transferring, for example, choosing an horizontal evacuation. The administrator of this facility also explained that he decided to evacuate the building some years ago because a landslide affected their area. In all the participating facilities the decision to evacuate is largely made by the administrators mainly in collaboration with external engineering consultants in case of major emergencies.

Only one facility reported having some troubles with the communication system. The administrator explained that the facility needed to improve the internal information flows so that all the staff could execute the same procedures during emergency without making their own decisions. The facility was also trying to improve the communication means, for example purchasing long-range two-way radios.

Only one facility had the resident medical and contact information digitally recorded. Medical charts of the residents were available online protected with a password and shared with the family members, the local social services and the referring physician of the patient. All the participating facilities usually transfer files with the individual residents, bagged in plastic to protect the paper files.

None of the facilities mentioned transportation-related issues.

Inclusive Emergency Preparedness

US facilities

None of the participating facilities included residents and their families in the emergency preparedness process. One administrator clearly explained that the facility addressed disability-related challenges (transportation and communication needs) but the information included on the emergency plan are not shared with residents. Another facility reported that nursing staff and social services keep residents informed during an evacuation. Furthermore, the Unit Manager provides a buddy system for residents who are visually or hearing impaired, or non-English speaking residents so these residents have access to information and a sense of security during the evacuation. It was not clear if the facilities recognized the importance of preparing their independent residents to handle emergency events so that the staff can concentrate their efforts on the more dependent residents during an emergency. The main concern of the facilities is how to handle with resident with cognitive and mental disabilities and they all stressed the importance of a trust relationship between the caregiver and the patient. This is a crucial issue that may influence which patients (physically or cognitive impaired) need to be evacuated first.

All the facilities were aware of the importance of this issue and they all recognized that they could do better in terms of including, at least, persons with physical disabilities in their emergency preparedness process. In terms of practical exercise, only one facility reported including residents in an evacuation drill. More often, due to the health conditions of the patients, facilities preferred conducting practical exercises with volunteers who act as residents. None of the facilities reported information on specific regulations that address the inclusion of residents and their families in emergency preparedness activities.

Italian facilities

None of the facilities involved their residents in the emergency preparedness process and there are no specific regulations or legislation in force that obliged the facilities to include residents as well as their families in the process. Although the administrators recognized the importance of social inclusion, they mentioned having many concerns on how to include patients with cognitive or mental disabilities. On the other hand, even those patients with physical disabilities are not involved in any way in the process.

With regard to practical exercises only one facility involved all the residents and their families in an earthquake drill. The administrator explained that usually they prefer to use the healthcare personnel acting as residents during emergency drill and however, family members were always notified before any simulation. Considering that the patients of this specific facility have serious cognitive deficits, the administrator stressed the importance to have a good and continuous dialogue on the emergency and evacuation procedures between staff and family members. In this sense, the facility included residents' families in the emergency preparedness process. The other three facilities did not include residents in practical exercises due to their often critical health conditions. Only one facility mentioned having specific patients handling techniques included in the emergency plan.

External collaborations

US facilities

All the facilities referenced working within their network to arrange assistance from other facilities. Some mentioned having contacts with utility companies like gas and water and with medical suppliers. One facility reported having a memorandum of understanding with various hospitals Another facility mentioned having good relationships with local emergency management office and fire department. In most cases, external emergency management agencies have information about the characteristics of

the facility and have a copy of the emergency plan but they have access to the residents' personal medical information only in case of evacuation.

Italian facilities

All the participating facilities explained that external first response teams do not have access to personal residents information prior to the event but only in case of a real emergency or evacuation. The information are provided directly on site by the healthcare staff. Only one facility shared some important information (type of disabilities within the facility and structural characteristics of the building) with the municipality and local fire department in order to facilitate the communication with first responders in case of emergency. Another facility reported sharing their emergency plan with local fire department and civil protection operators. One facility clearly expressed their will to create a strong collaboration with external first response teams and local emergency management agencies.

Concerns, strengths and areas of improvement

US facilities

Among the participating facilities the greatest worries and concerns were natural disaster and weather events. Not only were they concerned with high winds, tornados, ice, and snow, but also the associated power and utility outages. Fire was a concern, as was transportation and the logistics associated with evacuation, including knowing where to go, how to track patients and how to get them safely. One respondent specifically mentioned dealing with the challenges of transporting bariatric patients. Another facility reported having some communication problems during a disaster drill and therefore the administrative staff have focused on how is the best way to use the radios, for example how to keep the communication brief avoiding talking over one on other. Residents wellbeing was also a concern. Facilities want to keep residents safe, but were also worried about the negative health consequences that could come with evacuation.

Two facilities mentioned that staff was a concern. Specifically, the administrators were worried about the willingness of the staff to remain at work in case they have children at home. Consequently, the two facilities provided spare rooms and couches for the staff and their family members. The facilities also permit pets. The administrators reported that the staff were trained on this issue. The other two facilities directly stated that they were not concerned about the emergency preparedness and performance of their staff and even identified them as a strength.

Italian facilities

One facility posed the attention on the variety of the evacuation-related challenges considering that residents have a wide range of disabilities. Interview analysis showed different approach to the issue among facilities. In fact, one facility explained that in case of evacuation residents with dementia not represent an obstacle to evacuation procedures because they don't realize the seriousness of the situation and continue to behave as usual. Rather, the issue here is to ensure that staff is prepared to apply all the evacuation procedures described in the emergency plan and constantly tested during practical exercises. Conversely the other facilities believe that residents with dementia are the major concern in case of evacuation because they may hinder the evacuation procedures due to panic attack. As stated by the administrators the relationship between healthcare staff and residents play a key role for a successful evacuation. In this sense, practical exercises that include also the residents and their families represent a good opportunity to build trust in the relationship between staff and residents.

Another element of concern among facilities was the willingness of the staff to remain at work in time of emergency. Specifically, administrators revealed their concern in case of major emergencies and their impacts on the staff ability to stay focused on the emergency operations. Education on this issue in various forms was another next step for the facilities. More in detail, one facility explained that healthcare personnel is often little aware of the importance of training sessions and practical exercises. Consequently, the administrator increased training and exercise sessions trying to involve all the staff from different professional backgrounds (physicians, certified nurses, certified nurses assistants, technicians). The facility also reported updating periodically the emergency plan, increasing the number of fire safety personnel and restructuring the external emergency staircase.

Another facility stated that the internal alert system was improved and ensured that all the patients are assisted and supported in emergency and evacuation procedures by an operator also during the night shift. The same facility was scheduling a no-notice exercise to test the ability of the staff to respond to the first phases of emergency.

Only two facilities provided some information on available supplies such as food, water and drugs in case of sheltering in place. One facility reported having food and medications available for residents, staff and their families for a period of time no longer than 48 hours. Another facility specified providing food, water and medical supplies only in case of minor emergencies. No many details were given on this issue and even less on the opportunity of allowing staff families.

3.5.3 Earthquake Simulation Exercise

A debriefing exercise was conducted on October 29, 2014 in order to reconstruct the events of the exercise and to provide an opportunity for all participants to discuss how well the response of the players met the planned objectives and to share any lessons learnt from the exercise.

During the debriefing meeting, a video with the most significant events of the exercise was shared with all participants. A written detailed description of the exercise was distributed to all participants and then integrated with the insights emerged from the debriefing.

The emergency response team of the facility highlighted the following issues:

- improving the loudspeakers performance in some parts of the building;
- immediately after the earthquake, the emergency manager of the facility did not contact the daily shuttle drivers to give them important information on the emergency and evacuation procedures;
- the external emergency contact sheet should be more visible to the staff;
- in case of voluntary power cut-off the generator will not work, therefore the gates of the facility should be open before the power has been cut-off;
- during evacuation, the emergency manager could not use the cordless telephone and, as an alternative, he used the cordless in the sick bay;
- emergency role and responsibilities should not be overlapped that is those healthcare workers with a coordination role should remain
- in the assigned place to ensure the adequate execution of the evacuation procedures;
- the use of towel-bearers or any other patient handling technique should be evaluated not only in case of non-ambulant residents but also to support residents who walk very slow;
- emergency coordinators should be identified within the facility in order to facilitate the communication with the external emergency response teams;
- the effects of the evacuation on the residents was one of the main concerns of healthcare staff. The emergency response team of the facility reported no significant negative consequences on the health conditions of the residents.

The local fire department also stressed the importance to use individual protection devices during simulation exercise. Furthermore, all the staff (not only healthcare staff) should be adequately trained on patient handling techniques and many aspects such as transfer of medical information, availability of medical and specific food supplies deserve more attention.

3.6 Discussions And Conclusions

Little is published regarding the experience of staff and residents of long-term care facilities (LTCFs) and the importance of their participation to the emergency planning process and practical exercises. The existing literature focuses almost exclusively on the views of administrators and this is a notable shortcoming, as the health and well-being of residents are influenced directly by their routine daily interactions with direct care staff. Laditka (2009) stated that, in order to respond adequately to an emergency, a LTCF must rely on the skills, knowledge, commitment, active involvement and compassion of its direct care workers, in addition to preparation at the administrative level. Therefore, this study investigated the emergency preparedness of the staff and their awareness of the importance of training and exercises in caring for residents as well as the ability of the administrators to face emergency-related issues and more in details, disability-related challenges in emergency.

Statistical analysis of the survey revealed some significant differences between US and Italian healthcare staff in terms of emergency preparedness. Quarantelli (1997) states that the important part of planning is the process, not the product. Written plans are very important but they can be an illusion of emergency preparedness if other requirements such as training and exercise, are ignored (Quarantelli,1982b; Rosow,1977; Barton,1963; Barton,1969; Moore, 1958). This illusion is also known as the *"paper plan syndrome"*. Applying the statement of Gratz (1972) in this context, one of the reasons emergency plans become *"paper"* plans is because they are often composed by external consultants rather than by senior level administrative and healthcare staff who are directly responsible for carrying out the response. Although both US and Italian medical staff believed that planning and training were useful to better understand how to respond to an emergency, results revealed a stronger feeling of involvement in emergency planning among US staff. This result is reinforced by the interviews to the US administrators who tend to view the emergency plan more as a participatory on-going process rather than a mere product. Furthermore, the administrators of two Italian facilities reported relying on an external consultant (the *"Prevention and Protective Service Manager*") for the development of the emergency plan. Even though the administrators of those facilities reported that they review plans annually, it still seems as though their focus is on the product, counter to Quarantelli's recommendation.

Quarantelli (1997) also recommends taking a multi hazard or all hazard approach to planning for disasters, which all the US participating facilities say they do. Otherwise, only one Italian facility developed a multi-hazard emergency plan and included evacuation procedures in the emergency plan.

Likely as a consequence, results from the survey revealed that a high percentage of Italian healthcare personnel did not believe that the emergency plan gave a practical guidance on managing emergencies.

The scientific literature also stresses the need for practical exercises such as drills and tabletop exercises (Bowers, *et al* 2004; Brown 2007) in order to test emergency plans and adequacy of staff training. The results of the survey reinforced that fire drills are the most common and frequently types of emergency exercises conducted by LTCFs, but other more complex scenarios are also tested (Brown *et al.,* 2007). More in detail, fire drills were the most frequent type of practical exercise both in the US (quarterly and monthly) and Italian facilities (annually). About half of the Italian staff had never even taken part in fire drills. Other drills (hurricane and winter storm) were conducted more frequently in the US healthcare facilities (monthly and annually) whereas the largest part of the Italian staff had never even taken part in other drills such as earthquake and snow emergency. This result is consistent with Italian administrators' statements. Only one facility, in fact, conducted an earthquake drill and none of the Italian facilities conducted tabletop exercise counter to above cited authors. Survey results also revealed that the more the US and Italian staff consider themselves involved in the emergency planning, the more they feel trained and prepared to respond to an emergency. This result is a key aspect that reinforce the importance of involving the staff in the emergency preparedness process of the facility. All nursing staff should be involved in education meetings, training sessions and practical exercises. Furthermore, staff should receive concrete information about their performance during practical exercises and of course they should give their feedback in order to make program improvements. In order to develop an inclusive approach to emergency planning, long-term care facilities should implement training sessions and practical exercises as well as conduct debriefing exercises to identify strengths and areas of improvements in the execution of emergency procedures (e.g., patient handling techniques and evacuation procedures) and in training programs provided by the facility.

According to Saliba *et al.* (2004), one of the most commonly cited issues with emergency preparedness of nursing homes, after the Northridge Earthquake, was the absence of staff. Kendra *et al.* (2012) claimed that the issue of missing staff raises a number of significant questions that should be kept in mind by the administrators and healthcare staff of nursing facilities, such as how can the gaps left by missing staff members be filled where frail patients rely on staff to execute emergency and evacuation procedures as well as what factors influence staff members to focus on personal matters and abandon their roles. Interviews with administrators revealed that, although both US and Italian administrators were worried about their staff performance in case, for example, they had children at home, not many efforts have been made to support the needs of the staff and to think carefully about their personal

situations. However, US facilities seemed to be more confident with this issue and more aware of the importance of supporting staff and their family members in case of emergency. At this regard, two Italian facilities clearly expressed the need to sensitize the staff on this important issue through specific training sessions. It has to be said that no specific Italian regulations addressed this issue in the context of long-term care facilities and often, the administrators of such facilities, rely on the connection with the emergency management community (e.g. civil protection operators) in case of major emergencies that require further support. Further research is needed to understand how Italian regulations and policies can sensitize long-term care facilities on this specific issue.

According to Ruder (2012), involving residents and their families in training and exercise is crucial to preparation. In the context of long-term facilities the development of strategies for including the resident and their families in the emergency preparedness process may require administrators, nursing staff, residents and their families to work collectively in designing emergency plans and evacuation procedures. Both US and Italian Facilities reported that there are no specific regulations promoting the inclusion of residents and their families in the emergency preparedness process and therefore none of the participating facilities involved them in the decision-making process as well as in training and exercise sessions. US administrators reported having no specific regulations on this issue but, actually, the Centers for Medicare and Medicaid Services (CMS, 2007) published an emergency preparedness checklist as a *"recommended tool"* for healthcare facilities. In this important document the CMS clearly explained that it is crucial to ensure that residents and their families are aware of and knowledgeable about the facility emergency plan and furthermore, residents who are able to participate in evacuation should be aware of their roles and responsibilities in case of emergency. From the interviews with administrators clearly emerged that they mostly refer to the issue of inclusion in terms of specific emergency and evacuation procedures in the emergency plan and not to the inclusion of the residents and their families in the emergency preparedness process. In this sense they seemed to be little aware of the importance of the role played by residents in giving recommendations about how to include disability into a disaster response. At this regard, administrators should provide specific training to their staff to raise the sensitivity to issues of disability. This can provide a positive contribution that can make emergency services more accommodating for the residents of the facility. Furthermore, the facilities should immediately clarify that a proactive collaboration in terms of emergency preparation is expected from residents. This would ensure a stronger involvement of the residents in best preparing for an emergency or disaster. Finally, US and Italian healthcare facilities with physical impaired residents should view these residents as potential resources during an emergency. Indeed, scholars of emergency planning assert that including persons with disabilities in

the leadership of disaster management activities reduces their vulnerability and improves the effectiveness of the initiatives (United Nations Enable, nd) and this is in compliance with the underlying principle of *"full and effective participation and inclusion*" of the Convention on the Rights of Persons with Disabilities. Therefore, more specific policies on emergency preparedness of institutionalized persons need to be implemented at federal and state level in order to assist and support the staff of long-term facilities in caring patients during emergency situations as well as involving them in the emergency preparedness process. Fernandez et al. (2002) argue that the demand for mental health assistance for long term residents appears to be rather low and resources should instead be allocated to providing economic assistance during recovery. This important issue was mostly stressed by Italian facilities. Specifically, one Italian facility stressed the critical role of the staff in assisting the residents with cognitive disabilities and the importance of a proper mental preparedness of the staff and residents during emergencies.

With regard to practical exercises, it is important to consider the health conditions of the residents before including them in a practical exercise and to address their fears and concerns during and after drills. In fact, in case of emergency drills, some people with disabilities may experience heightened anxiety and may need to be exempt from participating. One-on-one emergency planning with these individuals may be a good alternative. Furthermore, during an emergency drill, it is not necessary for residents with mobility disabilities to evacuate the building completely. In alternative, those residents could be trained separately from general drills in assistance techniques; for example, how to use an evacuation chair, if one is available, or in transfer and carrying techniques (BC Coalition of People with Disabilities, 2008). At this regard, one Italian facility involved all the residents and their families in an earthquake drill in October 2014. Considering that the patients of this specific facility had serious cognitive deficits, the administrator stressed the importance of a good and continuous dialogue between the staff and the family members of residents on the emergency and evacuation procedures. In this sense, the facility included residents' families in the emergency preparedness process and distinguished itself for a more inclusive and integrated approach to emergency preparedness.

In order for nursing home administrators to ensure the wellbeing of their residents, efforts must be made to improve not just the facility's internal preparation, but its external network and operations as well (Kendra, 2012). According to a number of LTCFs administrators and staff, there is a chronic lack of connectivity between long-term care facilities and local emergency management agencies (Office of Inspector General, 2006). This is particularly true among Italian selected facilities sharing few information with local first response teams. All the Italian facilities explained that external first response teams do not have access to personal residents information prior to the event but only in case

of a real emergency or evacuation. Sharing specific information (e.g., type of disabilities of the residents and structural characteristics of the building) with the municipality and local fire department as a part of the emergency planning process would facilitate the communication between healthcare staff and first responders in case of a real emergency. One administrator clearly expressed his will to create a strong collaboration with external first response teams and local emergency management agencies. In turn, local emergency management systems can improve outcomes for residents by supporting the efforts of LTCFs on their behalf, including their needs in all relevant aspects of emergency planning and training (Hyer, Brown, Berman & Polivka-West, 2006).

Concluding, US participating facilities gave a more detailed description of their emergency preparedness and likely, they are more aware of the importance of some specific aspects of the whole process. This can be due, among other factors, to the fact that all the US selected facilities were part of a larger network where experiences and best practices are more likely to be spread and shared. Another important issue is the significant differences between US and Italian legal framework. Italian legislation does not address the specific issue of emergency preparedness in long-term care facilities and therefore standards for emergency plans and staff training are not established. Furthermore, all the US selected facilities were receiving Medicaid and/or Medicare funding and, therefore, they were subject to federal regulations and risk facing citations and fines if they do not meet established standards for emergency preparedness. In this sense, Italian sanction system and controls need to be implemented in order to guarantee a more adequate execution of emergency procedures. Finally, it must be stressed that both US and Italian policies need to be more specific on how to include the residents and their families in the emergency preparedness process of long-term care facilities. In turn, administrators and staff of such facilities should enhance their propensity for involving residents and their families in emergency preparedness, rather than simply follow what stated by the legislation. This important step towards an inclusive and integrated approach to emergency preparedness is more critical than ever considering the significant today's debate on the rights of persons with disabilities in emergency.

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Chapter 4:Conclusions and Future Research

This dissertation investigated the efforts in meeting the needs of persons with disabilities, with a focus on the emergency preparedness process of US and Italian long-term care facilities and Italian municipalities. In this final chapter, we will review the research contributions of this dissertation, as well as discuss directions for future research.

4.1 Contributions

The following are the main research contributions of this dissertation:

- **Mainstreaming Disability into Disaster Risk Reduction** - Chapter 1 provided an overview of various disability-related issues in emergency preparedness. The role played by the UN Convention on the Rights of Persons with Disabilities in protecting and promoting the rights of those persons in situations of emergency has been investigated as well as shortfalls in international policies with respect to the Convention. The literature review highlighted various negative issues experienced by persons with disabilities following Hurricane Katrina and Haiti earthquake as well as some successful disability-inclusive strategies in disaster preparedness and response.
- **Including persons with disabilities in municipal emergency preparedness** - Chapter 2 provided the results of the interviews conducted with the emergency management officials of three municipalities of Marche region. The study aimed to understand at which extent the needs of persons with disabilities were included in the municipal emergency plan and if those persons and their families were included in the emergency preparedness process. Furthermore, the results of the study were used to support the Department of Civil Protection of the Marche Region in developing guidelines for assisting persons with disabilities during situations of emergency and involving them in the emergency preparedness process.
- **Emergency preparedness of US and Italian long-term care facilities** - Chapter 3 focused on the differences between US and Italian staff in terms of emergency preparedness. Often affected by physical, cognitive and psychological disabilities, residents of such facilities must rely on the aid of staff, drugs, and medical equipment on a daily basis and, in case of emergency, they rely on

the ability of the staff to safely execute emergency and evacuation procedures. Therefore, the emergency preparedness process of the selected facilities was investigate in order to understand how they address the needs and rights of the residents in situations of emergency. The interviews with the administrators of the facilities included some significant disability-related issues such as evacuation procedures, safe patient handling techniques, transportation and communication systems, collaboration with external emergency management agencies and specific federal and state regulations on how to include residents and their families in emergency planning, training and practical exercises. Special attention was paid to a practical exercise conducted by Lega del Filo d'Oro, an Italian rehabilitation institute for children and adults with visual, hearing and cognitive disabilities. The earthquake simulation exercise involved all the staff and residents, the Civil Protection Department of the Marche Region, the municipal emergency management officials and the local first response teams (e.g., fire fighters, red cross, local police etc.). Given that the residents of the facility had serious cognitive deficits, the administrator stressed the importance of a continuous dialogue on emergency-related issues between staff and residents' families. In this sense, the facility distinguished itself for a more inclusive and integrated approach to emergency preparedness. Significant aspects and insights emerged during the debriefing exercise have been reported and discussed.

4.2 Further Research

The analysis of the scientific literature revealed that, although in many countries the protection and promotion of the rights of persons with disabilities are well underway, the dialogue on the needs of persons with disabilities in situations of emergency is not well developed. The lack of a robust network including governments, institutions and organizations of people with disabilities as well as people with disabilities and their families has resulted in inadequate and often, discriminatory emergency preparedness and response procedures. Promoting the inclusion of people with disabilities and their families in the emergency preparedness process would help stakeholders, decision makers and emergency management professionals to better identify areas in which those persons are discriminated and therefore, to develop disability-inclusive strategies in compliance with the human rights-based approach. Further research is needed to understand how integrate specific measures for persons with disabilities into national disaster risk reduction policies, emergency preparedness processes, training and exercise sessions as well as to promote investments in long-term strategies that would increase the safety of persons with disabilities and

their ability to respond to an emergency. Furthermore, it is highly recommended to define national standards for the assistance and rescue of persons with disabilities in case of emergency.

There is also lack of systematic data on persons with disabilities and few studies focused on how to include them in decision-making processes. The results of the study conducted in the Italian municipalities confirmed and reinforced the importance of building a dialogue on the issue of disability in emergency among various stakeholders and the need of collecting detailed information on persons with disabilities, including their addresses, ages, types of disability and specific needs during emergencies. This important activity, in fact, is often difficult due to privacy-related issues and the lack of cooperation among civil protection authorities, organizations of people with disabilities and local health authorities. Collecting this important information, before an emergency occurs, would be a starting point for the development of an inclusive emergency preparedness that consider persons with disabilities individually rather than as groups or categories. Therefore, further research is also needed to identify strategies for developing a local network of political authorities, public administrators, civil protection authorities and civil society organizations as well as organizations that provide care and representation to people with disabilities. It is also recommended to identify strategies to include persons with disabilities and their families in local emergency preparedness as well as sensitize them on the importance of participating to education programs and training and exercise sessions.

Special emergency planning provisions should be made for hospitals, long-term facilities and any other institute where people with disabilities are likely to be concentrated. Italian facilities should improve their collaboration with external emergency management agencies in order to develop integrated emergency plans and to implement training and exercise sessions. These activities, conducted prior to a disaster event, can facilitate the communication between healthcare staff and first response teams and, therefore, the evacuation and rescue operations. Further research should investigate the importance of implementing national regulations on this specific aspect of emergency preparedness of long-term care facilities. Furthermore, US and Italian regulations and policies need to be more specific on the inclusion of residents as well as their families in the emergency preparedness process and, in turn, the administrators and the staff of such facilities should enhance their propensity for involving residents and their families in emergency preparedness, rather than simply follow what stated by the legislation. This important step towards an inclusive and integrated approach to emergency preparedness is more critical than ever considering the significant today's debate on the rights of persons with disabilities in emergency situations.

Appendices to Chapter 2

Intervista ai comuni sull'inclusione delle persone con disabilità nelle attività di pianificazione dell'emergenza

Domande introduttive

1. All'interno del Comune qual è la sua funzione? Nello specifico quali sono le attività da lei svolte e da quanto tempo lavora nel suo ambito?

2. A quando risale l'ultimo aggiornamento del piano di emergenza del suo Comune? Quali modifiche sono state eventualmente apportate al piano in seguito alla legge n. 100/2012?

3. Quando lei pensa ad un possibile evento calamitoso che potrebbe coinvolgere il suo Comune, quali sono le sue maggiori preoccupazioni? Quali sono le maggiori problematiche che nel suo Comune si trova ad affrontare nella pianificazione dell'emergenza?

Inclusione delle persone con disabilità nei processi di pianificazione dell'emergenza:

4. Sarei interessata a comprendere meglio quali influenze ha avuto, sulla pianificazione comunale dell'emergenza, il rinnovato interesse per la tematica della disabilità.

5. A suo avviso che cosa significa includere le persone con disabilità nei processi di pianificazione dell'emergenza? Per l'elaborazione e la realizzazione dei piani di emergenza, l'Amministrazione Comunale si è confrontata con le persone con disabilità, le loro famiglie e le Associazioni che le rappresentano?
Ritiene che la piena partecipazione dei cittadini con disabilità e delle loro famiglie alla elaborazione del piano di emergenza e alle esercitazioni rappresenti un valore aggiunto per la pianificazione? Secondo la sua opinione, in che modo queste persone possono contribuire ad una più adeguata ed efficace pianificazione dell'emergenza?

6. La Classificazione Internazionale del Funzionamento, della Disabilità e della Salute (ICF, 2001) definisce la disabilità come "l'esito o risultato di una relazione complessa fra le condizioni di salute di un individuo, i fattori personali e quelli esterni che rappresentano le circostanze nelle quali vive" e pone al centro dell'attenzione l'interazione tra i fattori personali, ambientali e sociali. Per esaminare le problematiche inerenti la disabilità, la Protezione Civile comunale utilizza la classificazione ICF?

7. In che modo la legislazione nazionale e regionale può rappresentare una guida ed offrire valide strategie per integrare e coordinare le attività di pianificazione dell'emergenza con le persone con disabilità? La sua Regione ha emanato linee guida per la pianificazione comunale dell'emergenza con specifiche indicazioni sul tema della disabilità?

8. In che misura l'inclusione delle persone con disabilità nei processi di pianificazione dell'emergenza rappresenta un diritto e un dovere di queste persone?

Attenzione alla tematica della disabilità nei piani di emergenza comunali

8. All'interno del piano comunale di emergenza esiste una sezione specifica dedicata al tema dell'assistenza alle persone con disabilità in emergenza? Ad esempio, il piano contiene informazioni relative alle modalità di evacuazione e trasporto delle persone con disabilità? Esistono aree di raccolta e/o strutture predisposte (con assenza di barriere architettoniche) all'accoglienza di queste persone? Tali informazioni sono state inserite nel piano di emergenza e ne è stata effettuata una mappatura?

9. Secondo il Metodo Augustus, il Responsabile della Funzione Sanità e Assistenza Sociale predispone e coordina le squadre di volontari presso le abitazioni di persone non autosufficienti e/o bisognose di assistenza. Potrebbe specificare come questa funzione viene svolta in fase rispettivamente di preallarme e allarme nel suo Comune?

10. Il piano comunale di emergenza contiene dati circa le persone con disabilità (es: nome e cognome, indirizzo, tipologia di disabilità ecc.)? Da quale ente sono stati forniti questi dati e ogni quanto vengono aggiornati (es: ASL, Medico di medicina generale, Associazione di volontariato, ecc.)? Esiste una mappatura delle persone con disabilità, anche in relazione ai rischi presenti sul territorio, per facilitare l'assistenza e il soccorso in caso di emergenza?

11. Il piano di emergenza del suo comune è un documento consultabile da tutti la popolazione? Con quali modalità? Il piano esiste in versioni accessibili alle persone con disabilità? In quali formati (es: versione in lingua dei segni, versione in braille, formato in file sonoro)?

Accordi di collaborazione sul territorio

12. L'Amministrazione Comunale ha sottoscritto accordi di collaborazione con altri enti o associazioni per garantire l'assistenza e il soccorso alle persone con disabilità in caso di emergenza? Potrebbe specificare con quali enti o associazioni (es: ASL, associazioni di volontariato, ecc.)?

13. Nella Regione Marche, a seguito dell'entrata in vigore della legge regionale 4 Giugno 1996, n.18 *"Promozione e coordinamento delle politiche di intervento in favore delle persone in condizione di disabilità"*, è stata istituita la Consulta regionale per la disabilità (art.6). Il suo comune collabora o ha collaborato con la Consulta sulla tematica della disabilità in situazioni emergenziali? Ritiene che questa collaborazione rappresenti un valore aggiunto nel processo decisionale di pianificazione?

14. Il suo comune è in possesso di banche dati e/o mappature contenenti informazioni sulle strutture sanitarie e socio-assistenziali presenti sul territorio? In riferimento ad attività di pianificazione e gestione dell'emergenza, il suo Comune collabora con le Case di riposo, Centri Diurni e Istituti Riabilitativi sul territorio? Ad esempio, vengono svolte esercitazioni e/o prove di evacuazione? In fase di emergenza quale tipo di assistenza viene fornita a queste strutture?

Informazione, formazione ed esercitazioni

15. Il suo comune promuove specifiche iniziative di informazione per far conoscere il piano di emergenza alle persone con disabilità? Ad esempio, sono mai stati organizzati incontri informativi e formativi con la popolazione, campagne di sensibilizzazione sul tema della disabilità in emergenza tramite internet, radio, tv, cartellonistica?

16. Il suo comune ha mai organizzato corsi di formazione sulla tematica della disabilità per operatori di protezione civile, operatori di associazioni di volontariato e cittadini? Sono mai state organizzate esercitazioni sulla tematica della disabilità? Quali corsi ed esercitazioni sono stati organizzati, da quale ente e associazione e con quali modalità sono stati pubblicizzati?

Indirizzi regionali per una efficace inclusione delle persone con disabilità nelle attività di pianificazione dell'emergenza a livello comunale

Premessa

Questo documento vuole rappresentare un utile e sintetico vademecum per i Sindaci e per l'intera struttura comunale, volto all'inclusione delle persone con disabilità nel processo di pianificazione dell'emergenza a livello locale.

Naturalmente il primo obiettivo di tali linee guida è assicurare che nel piano comunale di emergenza siano inserite misure rivolte alle persone con disabilità, ma ancor più si vuole garantire l'inclusione di queste persone e di quanti orbitano a vario titolo in tale contesto nelle attività di pianificazione e prevenzione, poiché è ormai dimostrato che l'inclusione gioca un ruolo fondamentale nella salvaguardia dei diritti e doveri di tutti i cittadini in emergenza e, soprattutto, rappresenta un elemento chiave per la corretta pianificazione dell'emergenza rivolta a tutta la comunità.

Questo nuovo approccio, rappresentato dal modello sociale di disabilità dell'Organizzazione Mondiale della Sanità (OMS), recentemente integrato con il modello basato sui diritti umani, considera lo stato di salute delle persone in relazione ai loro ambiti di vita (sociale, familiare, lavorativo), intendendo la disabilità come uno stato di salute in un ambiente sfavorevole. Secondo questo approccio la disabilità, dunque, non è considerata come un problema di un gruppo minoritario, bensì un'esperienza che tutti nell'arco di una vita possono sperimentare.

Purtroppo, ad oggi, la maggior parte delle persone con disabilità non partecipa, o comunque non partecipa costantemente, alle attività di pianificazione e gestione dell'emergenza, né prende parte alle decisioni in merito a queste tematiche. Inoltre, spesso, le campagne di sensibilizzazione sul tema della preparazione all'emergenza non considerano le esigenze delle persone con disabilità, ponendo esse in una condizione di rischio maggiore nonché di esclusione ed emarginazione.

Nella stesura di questi indirizzi si è tenuto conto anche dei risultati ottenuti dall'indagine promossa dal 2011 dal Dipartimento della Protezione Civile, attraverso la collaborazione con la Cooperativa Europe Consulting, e inerente lo studio dell'approccio al tema della disabilità da parte delle strutture e componenti del Servizio Nazionale di Protezione Civile, oltre che dei risultati ottenuti attraverso la ricerca di dottorati istituiti presso l'Università Politecnica delle Marche in materia di "Protezione Civile e Ambientale".

Ciò premesso, il presente documento nasce per adempiere in modo più efficace e completo alla normativa vigente in materia di protezione civile che pone in capo alle regioni la formulazione di indirizzi di

programmazione e pianificazione, ma principalmente si rivolge agli attori del sistema comunale di protezione civile, affinché siano poste in atto le attività necessarie per dare risposta alle esigenze della popolazione disabile e delle loro famiglie, come pure di tutte le persone più fragili (anziani, bambini, donne in stato di gravidanza) in occasione di eventi emergenziali.

Criticità dell'emergenza in presenza di persone con disabilità

L'esperienza di un disastro per persone con disabilità può essere più acuta e di più lunga durata rispetto al resto della popolazione. Queste persone possono riscontrare differenze di accesso all'alloggio provvisorio e al soccorso e sono spesso escluse dalla piena partecipazione ai processi di pianificazione. In caso di terremoto, ad esempio, una persona su una sedia a rotelle non può rifugiarsi sotto un banco o un tavolo, né correre in strada passando dalle scale di un palazzo. Le persone sorde o non vedenti potrebbero non riconoscere un pericolo o non sentire istruzioni verbali, che intimino l'evacuazione. Per di più, le persone che dipendono da attrezzature elettriche (macchine per la dialisi, ventilatori) potrebbero trovarsi in difficoltà nel caso in cui la corrente elettrica venisse a mancare durante un'emergenza.

La fase di assistenza e soccorso ad una persona con disabilità durante un'emergenza è molto delicata e complessa. La complessità di questa fase è legata anche al fatto che esistono differenti tipologie di disabilità, quali:

- Disabilità motoria;
- Disabilità sensoriale: uditiva e visiva;
- Disabilità intellettiva;
- Disabilità psichica.

Gli elementi che possono determinare le criticità dell'emergenza in presenza di persone con disabilità dipendono da:

1. la mancanza di un censimento territoriale delle persone con disabilità e l'aggiornamento dei relativi dati personali che faciliti la loro inclusione nelle attività di pianificazione, nonché l'intervento tempestivo ed efficace durante la fase di risposta all'emergenza;
2. l'assenza di una rete di supporto territoriale alle strutture comunali, individuata durante la fase di pianificazione;
3. le modalità per garantire efficaci allertamenti e comunicazioni in emergenza;

4. la presenza di barriere architettoniche che limitano o annullano la possibilità di raggiungere un luogo sicuro in modo autonomo e la mancata individuazione e mappatura di aree/siti di emergenza/accoglienza accessibili a persone con disabilità;
5. la carente divulgazione della conoscenza del piano comunale di protezione civile, indirizzata a tutta la popolazione;
6. la mancanza di una formazione specifica d'intervento rivolta ai pianificatori, ai soccorritori e/o agli addetti alle operazioni di evacuazione sulle modalità di percezione, orientamento e fruizione degli spazi da parte delle persone con disabilità, con cui si dovrà interagire in emergenza.
7. Durante il soccorso ad una persona con disabilità è opportuno identificare il tipo di disabilità e comprendere le molteplici necessità della persona coinvolta nell'emergenza. Il soccorritore, inoltre, deve essere in grado di comunicare un primo e rassicurante messaggio che specifichi le azioni basilari da intraprendere.

Tutto ciò rende evidente l'esigenza di un protagonismo da parte delle persone con disabilità durante le attività di pianificazione e gestione dell'emergenza. Esse per prime dovrebbero agevolare le operazioni di soccorso in emergenza preparandosi e rendendosi facilmente localizzabili sul territorio, in una logica di autodifesa ma anche di supporto attivo all'intervento del sistema di protezione civile che opera sul territorio.

Centro Operativo Comunale (COC)

La Regione Marche con DGR 800/2012 ha approvato i "Requisiti minimi dell'organizzazione locale di protezione civile", con l'obiettivo di migliorare e ottimizzare la capacità di allertamento, di attivazione e di intervento del sistema locale di protezione civile a fronte di eventi calamitosi, prevedibili e non, nonché di creare la necessaria risposta di intervento in termini di protezione civile al verificarsi di un determinato pericolo e/o avversità calamitosa. In tale documento viene rimarcata la necessità di *individuare unità di personale interno all'amministrazione per il necessario coordinamento delle operatività nelle situazioni di allarme od emergenza, in particolare con compiti, tra gli altri, di "assistenza socio-sanitaria"*.

Come noto il Metodo Augustus fornisce un indirizzo per la pianificazione di emergenza e introduce le "funzioni di supporto", che rappresentano *l'organizzazione delle risposte che occorre dare alle diverse esigenze presenti in qualsiasi tipo di evento calamitoso, con dei responsabili in modo da tenere "vivo" il*

piano, anche attraverso periodiche esercitazioni ed aggiornamenti e che possono essere istituite in maniera flessibile.

Per quanto concerne la pianificazione dell'emergenza il Metodo Augustus delinea inoltre gli obiettivi che le autorità territoriali devono conseguire per mantenere la direzione unitaria dei servizi di emergenza a loro delegati. Tra questi obiettivi la "salvaguardia alla popolazione", compito prioritario del Sindaco in qualità di Autorità di protezione civile, è di particolare interesse in questo contesto, poiché sottolinea l'importanza di dare particolare riguardo alle persone con ridotta autonomia quali anziani, disabili, bambini e di attuare piani particolareggiati per l'assistenza alla popolazione (aree di accoglienza, ecc.).

In relazione alla tematica trattata nel presente documento, vogliamo porre l'attenzione sulla funzione di supporto "Sanità – assistenza sociale – veterinaria", come indicato nel metodo Augustus o in modo equivalente sulle unità di personale con compiti di "assistenza socio-sanitaria", riportata nella DGR 800/2012, i cui referenti, generalmente designati dal Servizio Sanitario Locale, dovranno tra l'altro coordinare gli interventi di natura sanitaria e gestire l'organizzazione dei materiali, dei mezzi e del personale sanitario (appartenenti alle strutture pubbliche, private o alle associazioni di volontariato operanti in ambito sanitario). Tale funzione di supporto potrà essere quella individuata in seno al Centro Operativo Comunale (COC) anche per la gestione dei dati delle persone con disabilità presenti sul territorio, sia per quanto riguarda il soccorso in emergenza, sia per quanto concerne l'inclusione di esse nelle attività di pianificazione (esercitazioni, incontri formativi e informativi in merito al piano di emergenza comunale).

Alla luce di quanto premesso, al fine di dare risalto alla tematica dell'inclusione della disabilità, si suggerisce di utilizzare una differente definizione per tale funzione, modificandola in <u>funzione di supporto "Sanità – veterinaria – assistenza sociale – disabilità" o "assistenza socio-sanitaria e disabilità"</u>, evidenziando in tal modo chiaramente l'ambito di intervento rivolto anche alla organizzazione delle risposte derivanti dalle esigenze delle persone con disabilità.

Va sottolineato che risulta fondamentale la presenza di personale formato nella gestione delle persone con disabilità nell'ambito della funzione di supporto "Sanità – veterinaria – assistenza sociale – disabilità", o in modo equivalente, "assistenza socio-sanitaria e disabilità" e tale personale dovrà curare i rapporti con la rete di supporto territoriale alle strutture comunali, individuata durante la fase di pianificazione, e con gli enti preposti al soccorso (VVF, sistema territoriale di emergenza sanitari 118,..) e all'assistenza, dando indicazioni precise sull'ubicazione e sul tipo di necessità specifiche dei cittadini in questione.

Il censimento territoriale delle persone con disabilità e protezione dei dati personali, ai fini della pianificazione di un intervento di protezione civile

Per poter pianificare un intervento nei confronti delle persone con disabilità, è fondamentale conoscere dove vivono e quali sono le loro necessità specifiche. Per questa ragione è di particolare importanza avere un censimento delle persone disabili che vivono nel territorio (estratto dalla rivista "PROTEZIONE CIVILE" anno 4 n. 14) e la relativa mappatura.

Occorre pertanto creare un legame tra il Comune e tutti i soggetti che normalmente si occupano di disabilità sul territorio e a tal riguardo va sottolineata *l'importanza di utilizzare l'ICF (International Classification of Functioning, Disability and Health - WHO), la classificazione internazionale del funzionamento, disabilità e salute per esaminare i problemi delle persone con disabilità, poiché tale classificazione parte dal presupposto che la disabilità può essere un'esperienza universale, perché ogni essere umano può trovarsi in un ambiente con caratteristiche che possono limitare o restringere le sue capacità funzionali e di partecipazione sociale. Da questo dato emerge* l'importanza di una specifica formazione per il personale addetto alla redazione dei piani di emergenza.I dati relativi alle persone con disabilità possono essere forniti da:

- uffici comunali, quali Servizi Sociali, Servizio Anagrafe, …;
- strutture sanitarie delle Aree Vaste ASUR territorialmente competenti;
- MMG (medici di medicina generale) e PLS (pediatri di libera scelta);
- Associazioni di categoria (rappresentanti delle persone con disabilità motorie e sensoriali, persone anziane con disabilità moderate, invalidi da infortuni sul lavoro, …);
- Organizzazioni di volontariato.

Il censimento dovrà considerare anche i soggetti dipendenti da apparecchiature elettromedicali a domicilio e va sottolineato che la loro autonomia in termini temporali è fortemente legata alla tipologia di apparecchiatura utilizzata: in linea di massima i tempi di intervento possono variare dalle 1-2 ore fino alle 24 ore.

Risulta utile ricordare, inoltre, che nella Regione Marche, a seguito della entrata in vigore della Legge Regionale 04 giugno 1996, n. 18 "Promozione e coordinamento delle politiche di intervento in favore delle persone in condizione di disabilità", è stata istituita la Consulta regionale per la Disabilità (art. 6), di cui fanno parte le seguenti associazioni: **AIAS** (ASSOCIAZIONE PROFESSIONALE ITALIANA AMBIENTE E SICUREZZA), **AICG** (ASSOCIAZIONE ITALIANA CENTRI GIARDINAGGIO), **ALITO** (ASSOCIAZIONE DI VOLONTARIATO PER LA TUTELA DELLA SALUTE DEI BAMBINI

HANSENIANI – TBC – AIDS DEL TERZO MONDO), **ANFFAS** (ASSOCIAZIONE NAZIONALE FAMIGLIE DI PERSONE CON DISABILITA' INTELLETTIVA E/O RELAZIONALE), **ANICI** (ASSOCIAZIONE NAZIONALE INVALIDI CIVILI E CITTADINI ANZIANI), **ANIEP** (ASSOCIAZIONE NAZIONALE PER LA PROMOZIONE e la difesa dei diritti delle persone disabili), **Anmic** (Associazione Nazionale Mutilati e Invalidi Civili), Anmil (Associazione Nazionale Mutilati e Invalidi del Lavoro), **Anmig** (Associazione Nazionale Fra Mutilati e Invalidi di Guerra), **Anvcg** (Associazione Nazionale Vittime Civili di Guerra), **APM** (ASSOCIAZIONE PARAPLEGICI DELLE MARCHE), **Ens** (ENTE NAZIONALE SORDI), **Gruppo Solidarietà, Lega del Filo d'Oro, UIC** (UNIONE ITALIANA CIECHI E DEGLI IPOVEDENTI), **UILDM** (UNIONE ITALIANA LOTTA ALLA DISTROFIA MUSCOLARE) **di Ancona e di Colbordolo**, **UNMS** (UNIONE NAZIONALE MUTILATI PER SERVIZIO).

Particolare rilievo assume nell'ambito del censimento territoriale delle persone con disabilità "la protezione dei dati personali ai fini della pianificazione di un intervento di protezione civile".

Il D.Lgs. N. 196 del 30/06/2003 rappresenta il Codice in materia di protezione dei dati personali e gli artt. 20, comma 2 e 21, comma 2 recitano:

Nei casi in cui una disposizione di legge specifichi la finalità di rilevante interesse pubblico, ma non i tipi di dati sensibili e giudiziari trattabili ed i tipi di operazioni su questi eseguibili, il trattamento è consentito solo in riferimento a quei tipi di dati e di operazioni identificati e resi pubblici a cura dei soggetti che ne effettuano il trattamento, in relazione alle specifiche finalità perseguite nei singoli casi.

Ciò significa in linea di principio che la P.A. deve dichiarare ai cittadini in modo trasparente che cosa intende fare dei dati personali che intende trattare, pena l'illecito. Tale esigenza di trasparenza amministrativa impone che la identificazione dei dati da trattare deve avvenire con atto di natura regolamentare adottato in conformità a un parere espresso dal Garante (settembre 2005, dicembre 2005, aprile 2006).

Tenuto conto che la protezione civile rientra tra le attività istituzionali indispensabili, ai sensi del D.Lgs. 196/2003, art. 73 comma 1, lett. b) e comma 2 lett. h), il Garante ha rilasciato in diverse occasioni pareri in tale ambito e in particolare ha risposto ad un preciso quesito formulato dal DPC in data 31 ottobre 2008, inerente il *"Trattamento dei dati personali ai fini di protezione civile"*, che chiarisce come non sussistano ostacoli di fondo alla legittima acquisizione da parte dei comuni dei dati idonei a garantire la

predisposizione e la realizzazione dei piani di emergenza, ma tale individuazione va fatta dal comune mediante il regolamento consiliare, nello schema fac simile già approvato dal Garante nel 2005.
Questo significa che il parere del Garante del 2005, che ha sancito la titolarità della protezione civile locale a trattare i dati personali, richiede che gli enti locali adeguino i propri Regolamenti con una delibera di modifica, introducendo una apposita scheda di riferimento per i piani di protezione civile, secondo le indicazioni del Garante (il quale per semplificare le procedure ha approvato alcuni schemi tipo da adottare senza ulteriori verifiche).Tutto ciò premesso, al fine di agevolare il Comune nella redazione degli atti necessari al reperimento e al trattamento dei dati sulle persone con disabilità, ai fini della pianificazione di un intervento di protezione civile, garantendo al contempo la protezione dei dati personali come richiesto dalle norme vigenti in materia, vengono riportati nell'ALLEGATO 1 al presente documento: i riferimenti normativi, le indicazioni e gli schemi funzionali all'esercizio delle attività di che trattasi, ed anche, a titolo esemplificativo, uno schema di Delibera di un Consiglio Comunale.

Banche dati e aggiornamento del censimento territoriale delle persone con disabilità

La raccolta e l'aggiornamento dei dati sulle persone con disabilità sono attività di fondamentale importanza per consentire una corretta mappatura, che metta in relazione le diverse forme di disabilità con l'analisi delle differenti tipologie di rischi che insistono sul territorio (sismico, meteo-idro, incendio boschivo o di interfaccia, industriale, ecc), anche preventivamente individuando le aree più vulnerabili del territorio.
Risulta inoltre auspicabile la presenza di piattaforme informatiche inserite nel sito web di ogni Comune, dove le persone con disabilità (o tramite loro parenti/assistenti) abbiano la possibilità di registrarsi volontariamente (dotandosi di ID e password), fornendo i propri dati per la localizzazione sul territorio e per l'indicazione della tipologia di disabilità e delle necessità relative all' assistenza e al soccorso in emergenza (comunicazione, trasporto, medicinali, ecc). Le banche dati dovrebbero contenere inoltre informazioni sulle *strutture sanitarie e socio-assistenziali presenti sul territorio* e una pianificazione inclusiva potrebbe partire proprio dal considerare i residenti di tali strutture. Si ritiene infatti che la pianificazione per questa tipologia di strutture sia agevolata, poiché si suppone che abbiano già analizzato e organizzato la risposta alle emergenze, in funzione delle loro peculiarità e criticità nella redazione del piano di emergenza interno. Con queste strutture il Comune dovrà, a maggior ragione, collaborare e organizzare attività finalizzate ad una corretta pianificazione e gestione dell'emergenza. Il Comune potrà testare attraverso incontri ed esercitazioni congiunte, il livello di preparazione nel soccorso e

nell'assistenza dei residenti che presentano diverse tipologie di disabilità. Quindi, anche queste strutture e le loro caratteristiche (strutturali e non) dovranno essere preventivamente individuate sul territorio per pianificare un adeguato intervento in emergenza.

La rete di supporto territoriale alle strutture comunali

Nell'ottica di un processo di individuazione di buone pratiche per un'efficace inclusione delle persone con disabilità nelle attività di pianificazione di emergenza comunale, deve essere creata nel territorio una rete di collaborazione con tutti i soggetti che ordinariamente si occupano di disabilità e che coincidono, d'altra parte, con le strutture in grado di fornire i dati relativi alla popolazione disabile:

- Istituzioni;
- Strutture sanitarie delle Aree Vaste ASUR territorialmente competenti;
- MMG (medici di medicina generale) e PLS (pediatri di libera scelta);
- Associazioni di categoria;
- Organizzazioni di volontariato.

Inoltre, le stesse persone con disabilità, possono afferire a personale interno del Comune, a Cooperative sociali, ad associazioni di categoria, a volontari in Servizio Civile Nazionale, al volontariato di protezione civile, ecc.

Tale rete di supporto può essere rafforzata attraverso la stipula di accordi formali di collaborazione per garantire l'assistenza e/o soccorso alle persone con disabilità in caso di emergenza, ma in particolare deve essere coinvolta per l'elaborazione e la realizzazione dei piani di emergenza, tramite l'istituzione di tavoli di lavoro, seminari tematici a cui dovranno partecipare le persone con disabilità.

Si ritiene di particolare utilità inoltre, e proprio ai fini di una maggiore efficacia del processo di pianificazione dell'emergenza, l'organizzazione di corsi o giornate di formazione sul tema della disabilità che vedano coinvolti i rappresentanti delle strutture comunali, delle diverse strutture che compongono la rete di supporto territoriale e gli operatori in genere del sistema locale di protezione civile.

Efficaci allertamenti e comunicazioni in emergenza

Ciascun Comune deve essere sempre in grado di diramare le allerte e più in generale le comunicazioni in emergenza a tutti i cittadini. E' fondamentale quindi che il Comune promuova:

- appropriate forme di assistenza e di sostegno a persone con disabilità per assicurare il loro accesso alle informazioni, anche considerando la possibilità che vi sia la necessità di utilizzare lingue diverse dalla lingua italiana ;
- l'accesso per le persone con disabilità alle nuove tecnologie ed ai sistemi di informazione e comunicazione, incluso Internet;
- l'individuazione e la distribuzione di tecnologie e sistemi accessibili di informazione e comunicazione.

Il tema dell'allertamento è uno degli aspetti più critici nell'ambito della gestione dell'emergenza. Generalmente gli strumenti più utilizzati sono:

- megafoni;
- allertamento porta a porta;
- sirene.

Più raramente vengono impiegati pannelli luminosi, sms verso la popolazione o apposite App. sperimentali. Relativamente al tema dell'informazione e della comunicazione in emergenza gli strumenti maggiormente utilizzati sono:

- informazione porta a porta;
- sito web istituzionale;
- messaggi attraverso tv e radio;

ma possono essere previsti anche numero verde, email o modulo on-line, pagina facebook o twitter dell'amministrazione comunale. A tal proposito si sottolinea la necessità che i Comuni prevedano nel piano di emergenza procedure specifiche per allertare, informare e comunicare con le persone con disabilità, sviluppando modalità, che verranno divulgate in ordinario e testando tali attivazioni in apposite esercitazioni che coinvolgano l'intera popolazione. I Comuni di maggior dimensione demografica, costituiti da più circoscrizioni, potranno prevedere l'attivazione di uno o più luoghi appositamente dedicati alla divulgazione delle informazioni in emergenza, accessibili alle persone con disabilità, inseriti nel COC e/o distribuiti nel territorio. Anche in questo caso risultano utili i segnali Braille e la creazione di documenti in formati facilmente leggibili e comprensibili, il supporto da parte di persone addestrate e i servizi di mediazione, specialmente guide, lettori e interpreti professionisti esperti nel linguaggio dei segni, allo scopo di agevolare l'accessibilità all'informazione e di rendere la comunicazione più efficace possibile rispettando così i criteri di capillarità dell'informazione.

Accessibilità e mappatura delle aree di emergenza e di strutture ricettive

Le aree di emergenza e le strutture ricettive devono essere accessibili alle persone con disabilità. Il D.M. 236 del 14/6/1989 definisce l'accessibilità come la possibilità, anche per persone con ridotta o impedita capacità motoria o sensoriale, di raggiungere un'area o una struttura, di entrarvi agevolmente e di fruirne degli spazi e attrezzature in condizioni di adeguata sicurezza e autonomia.

Questo comporta la necessità di eliminare le barriere architettoniche ovvero:

- gli ostacoli fisici che sono fonte di disagio per la mobilità di chiunque ed in particolare di coloro che, per qualsiasi causa, hanno una capacità motoria ridotta o impedita in forma permanente e temporanea;
- gli ostacoli che limitano o impediscono a chiunque la comoda e sicura utilizzazione di parti, attrezzature o componenti;
- la mancanza di accorgimenti e segnalazioni che permettono l'orientamento e la riconoscibilità dei luoghi e delle fonti di pericolo per chiunque e in particolare per i non vedenti, per gli ipovedenti e per i sordi.A titolo di esempio, è fortemente consigliato dotare tali aree di segnali Braille e la creazione di documenti in formati facilmente leggibili e comprensibili, il supporto da parte di persone o di animali addestrati e i servizi di mediazione, specialmente di guide, di lettori e interpreti professionisti esperti nel linguaggio dei segni allo scopo di agevolare l'accessibilità. Nei piani di emergenza devono essere previsti:
- punti di raccolta, anche in contesti di strutture pubbliche quali scuole, biblioteche o centri sportivi;
- aree di emergenza o strutture per il ricovero della popolazione accessibili alle persone con disabilità.

Tali spazi devono essere mappati e ne vanno dettagliati i requisiti nei piani di emergenza, in termini soprattutto di accessibilità e servizi primari:

- dimensioni dell'area o descrizione degli spazi fruibili della struttura;
- accessibilità dell'area (es. larghezza collegamenti stradali,ecc) o della struttura;
- distanza dai fabbricati;
- presenza servizi primari quali acqua e luce;
- presenza servizi igienici accessibili alle persone con disabilità (rapporto numero servizi per popolazione);
- prossimità alle strutture sanitarie.

Attraverso la collaborazione delle strutture afferenti alla rete di supporto territoriale al Comune (es. associazioni di volontariato), vanno pianificati sia l'utilizzo di mezzi adeguati per il trasporto delle persone disabili con disabilità (specie laddove vi sia la necessità di organizzare l'evacuazione della popolazione) sia la disponibilità di appositi ausili quali bastoni o carrozzine. Tali punti di raccolta, aree o strutture vanno adeguatamente segnalati, e in modo permanente, attraverso apposita segnaletica.

Iniziative di formazione e informazione per far conoscere il piano di emergenza alla popolazione e, in particolare le misure rivolte alle persone con disabilità

La conoscenza del Piano di emergenza da parte della popolazione è l'elemento fondamentale per rendere un piano efficace, tanto più laddove si renda necessario sviluppare specifiche iniziative, come nel caso delle persone con disabilità.

Deve esistere un patto di mutua e solidale collaborazione tra i diversi livelli istituzionali nel perseguire il benessere e la sicurezza della popolazione e allora contestualmente potremo promuovere davvero la partecipazione attiva dei cittadini. Questo presuppone la *creazione* di una comunità locale resiliente, *"consapevole di convivere con i rischi accettabili, e capace di reagire in modo attivo ed integrato con le Autorità locali*" (E. Galanti, 2010).

Il Piano di emergenza deve essere consultabile dalla popolazione, in forma cartacea direttamente nella sede del Comune oppure in formato elettronico dal sito web del Comune o tramite applicazione su smartphone, e per quanto attiene alle persone con disabilità deve esistere in versioni accessibili, quali lingua dei segni, in braille o in formato di file sonoro.

Devono essere promosse iniziative per informare la popolazione sui rischi del territorio e sul Piano di emergenza comunale, attraverso:

- incontri, eventi, convegni, mostre;
- campagne di sensibilizzazione tramite radio, tv e cartellonistica;
- brochure/depliant informativi;
- locandine affisse nei luoghi di lavoro;
- numero verde;
- aggiornamenti sul web;
- informazioni sui social media (facebook, twitter);
- applicazioni su smartphone,

e tali iniziative devono essere sviluppate affinché possano essere informati in modo adeguato anche gli anziani, i bambini e le persone con disabilità.

Le esercitazioni sono il mezzo fondamentale per rendere operativo il piano di emergenza anche e soprattutto in presenza di persone con disabilità e/o fragili, non prescindendo da specifiche attività formative rivolte a tutto il personale degli enti e delle strutture operative del sistema locale di protezione civile, ma soprattutto coinvolgendo tutti i cittadini.

Ulteriori suggerimenti

i) Promuovere il dialogo tra i responsabili della pianificazione e gestione dell'emergenza e i rappresentanti delle associazioni per persone con disabilità e il coinvolgimento di questi ultimi nei processi decisionali legati alla pianificazione dell'emergenza;

ii) Spostare l'attenzione sulle abilità residue del soggetto in un'ottica di piena comprensione delle questioni legate alla disabilità in emergenza, in collaborazione anche con un team di esperti del settore (medici, infermieri, educatori, assistenti sociali, psicologi);

iii) Sensibilizzare le persone con disabilità sul tema della formazione e promozione della capacità di autosoccorso in emergenza;

iv) Creare corsi per gli operatori di protezione civile sulle tecniche di soccorso a persone con disabilità con relativo approfondimento sulle tipologie di disabilità esistenti in un'ottica di approccio diversificato;

v) Organizzare incontri formativi e informativi che coinvolgano le persone con disabilità e i loro rappresentanti circa il piano di emergenza comunale e i rischi presenti sul territorio, nonché esercitazioni e dimostrazioni pratiche che prevedano l'evacuazione così da testare le varie fasi dell'emergenza.

[doc. web n. 1213424]

Enti locali: ulteriori indicazioni sul trattamento dei dati sensibili e giudiziari - 29 dicembre 2005

IL GARANTE PER LA PROTEZIONE DEI DATI PERSONALI

Nella riunione odierna, in presenza del prof. Francesco Pizzetti, presidente, del dott. Giuseppe Chiaravalloti, vice presidente, del dott. Mauro Paissan e del dott. Giuseppe Fortunato, componenti, e del dott. Giovanni Buttarelli, segretario generale;

Visto il Codice in materia di protezione dei dati personali (d.lg. 30 giugno 2003, n. 196);

Vista la documentazione in atti e, in particolare, l'allegato A) recante l'elenco degli enti locali che hanno chiesto al Garante di esprimere un ulteriore parere in tema di trattamento dei dati sensibili e giudiziari non considerati negli schemi tipo già esaminati dall'Autorità;

Viste le osservazioni dell'Ufficio, formulate dal segretario generale ai sensi dell'art. 15 del regolamento del Garante, n. 1/2000;

Relatore il prof. Francesco Pizzetti;

CONSIDERATO:

1. Premessa
Di recente (in data 7, 21 settembre e 19 ottobre 2005) il Garante ha espresso parere favorevole sugli schemi tipo di regolamento per il trattamento dei dati sensibili e giudiziari predisposti, rispettivamente, dall'Upi (Unione delle province d'Italia) per le province, dall'Anci (Associazione nazionale comuni italiani) per i comuni, nonché dall'Uncem (Unione nazionale comuni comunità enti montani) per le comunità montane. Pertanto, qualora adottino i propri atti regolamentari in conformità a tali schemi tipo, gli enti locali non devono richiedere all'Autorità un ulteriore parere specifico per poter trattare dati sensibili e giudiziari (*cfr. art. 20, comma 2, del Codice*).

Alcune amministrazioni locali, in relazione alla specifica attività svolta, intendono però utilizzare dati sensibili o giudiziari in altri casi non considerati, oppure mediante altre operazioni di trattamento, che non sono stati parimenti sottoposti all'esame del Garante dalle predette associazioni. Sono quindi pervenute a questa Autorità ulteriori specifiche richieste di parere su schemi di regolamento per il trattamento dei dati sensibili e giudiziari predisposti da province, comuni e comunità montane (*artt. 4, comma 1, lett. d) ed e) e 154, commi 1, lett. g), e 5, del Codice*).

Tali richieste di parere, evidenziano questioni comuni e sono pertanto esaminate congiuntamente con il presente parere.

OSSERVA:

2. Dati sulla salute trattati da comuni e comunità montane nelle attività di protezione civile
Comuni e comunità montane hanno rappresentato la necessità di trattare dati idonei a rivelare lo stato di salute degli interessati anche nell'ambito delle competenze che la legge demanda loro in materia di protezione civile.

Valutate le circostanze che sono state rappresentate appare lecito che comuni e comunità montane trattino informazioni idonee a rivelare lo stato di salute di cittadini per lo svolgimento delle competenze che la legge demanda loro in materia di protezione civile.

I dati potranno essere raccolti su iniziativa degli interessati, ovvero presso altri soggetti pubblici o privati, e potranno essere trattati in forma sia cartacea, sia telematica, in particolare a fini di programmazione dei piani di emergenza o per dare attuazione, in caso di calamità, ai piani di evacuazione (*art. 73, comma 2, lett. h), del Codice; art. 108*

d.lg. 31 marzo 1998, n. 112; art. 6 legge 24 febbraio 1992, n. 225).

Sui dati potranno essere eseguite solo le operazioni ordinarie di trattamento elencate nello schema tipo dell'Anci. Le medesime informazioni potranno essere comunicate solo ai soggetti coinvolti nelle azioni di intervento, in particolare alle associazioni di volontariato operanti nella protezione civile, alle aa.ss.ll., al Dipartimento della protezione civile, a competenti prefetture, a province e regioni.

I dati utilizzati e le operazioni del trattamento compiute devono risultare indispensabili rispetto alle finalità perseguite nei singoli casi (*art. 22, comma 3, del Codice*).

3. Conferimento di onorificenze e di ricompense

Comuni e province hanno chiesto il parere del Garante in ordine al trattamento di dati sensibili e giudiziari finalizzato al conferimento di onorificenze e di ricompense, nonché al rilascio e alla revoca di autorizzazioni o di abilitazioni, di concessione di patrocini, di patronati e di premi di rappresentanze, di adesione a comitati d'onore e di ammissione a cerimonie e ad incontri, nell'ambito delle rilevanti finalità di interesse pubblico previste dall'art. 69 del Codice.

Valutate le circostanze che sono state rappresentate appare lecito che, con riferimento a tali finalità, comuni e province trattino i dati idonei a rivelare l'origine razziale ed etnica, le convinzioni religiose, filosofiche o di altro genere, le opinioni politiche, l'adesione a partiti, sindacati, associazioni od organizzazioni a carattere religioso, filosofico, politico o sindacale, patologie attuali o pregresse, nonché i dati giudiziari.

Potranno essere effettuati raffronti con dati personali, sensibili o giudiziari, detenuti da altre amministrazioni e da gestori di pubblici servizi, anche mediante eventuali interconnessioni; ciò, esclusivamente, ai fini dell'accertamento d'ufficio di stati, qualità e fatti, ovvero del controllo su dichiarazioni sostitutive prodotte dagli interessati (*v. art. 43 d.P.R. 28 dicembre 2000, n. 445*).

Potrà procedersi all'eventuale diffusione di dati per mezzo della pubblicazione all'albo pretorio delle pertinenti deliberazioni contenenti le predette informazioni (*d.lg. 18 agosto 2000, n. 267*). Ciò, tuttavia, in conformità al principio secondo cui la diffusione di dati sensibili e giudiziari trattati per concedere benefici economici, agevolazioni, elargizioni, altri emolumenti ed abilitazioni può avvenire solo se la loro indicazione nelle deliberazioni pubblicate sia indispensabile, in conformità alle leggi, per la trasparenza, la vigilanza e il controllo, fermo restando il divieto di diffondere dati idonei a rivelare lo stato di salute (*artt. 22, comma 8, e 68, comma 3, del Codice*).

I dati utilizzati e le operazioni del trattamento compiute devono risultare indispensabili rispetto alle finalità perseguite nei singoli casi (*art. 22, comma 3, del Codice*).

4. Agevolazioni tributarie

In materia di concessione, liquidazione, modifica e revoca di benefici economici, agevolazioni, elargizioni, altri emolumenti ed abilitazioni, ivi inclusi i finanziamenti in favore di associazioni, fondazioni ed enti, taluni schemi di regolamento comunale sui quali viene chiesto il parere del Garante identificano ulteriori dati sensibili oltre quelli individuati nella scheda n. 20 dello schema tipo di regolamento per i comuni.

Valutate le circostanze che sono state rappresentate appare lecito che i comuni, con riferimento a tale rilevante finalità di interesse pubblico e in aggiunta a quanto previsto nella medesima scheda 20 (*art. 68, comma 1, lett. f), del Codice*), trattino anche i dati idonei a rivelare convinzioni religiose, filosofiche, politiche o di altro genere. Ciò, in relazione ai casi in cui i comuni concedano agevolazioni tributarie ovvero, in conformità a leggi e regolamenti, utilizzino fondi derivanti da oneri di urbanizzazione o da contributi regionali per interventi relativi ad edifici di culto, a pertinenze funzionali all'esercizio del culto, nonché a sedi di partiti ed associazioni.

I dati utilizzati e le operazioni del trattamento compiute devono risultare indispensabili rispetto alle finalità perseguite nei singoli casi (*art. 22, comma 3, del Codice*).

5. Attività ricreative, promozione della cultura e dello sport ed occupazioni di suolo pubblico

Nell'ambito delle rilevanti finalità di interesse pubblico di cui all'art. 73 del Codice, taluni enti locali prevedono il trattamento di dati personali sensibili per attività ricreative o di promozione della cultura dello sport, ovvero per l'uso di beni immobili o per l'occupazione di suolo pubblico.

Valutate le circostanze che sono state rappresentate appare lecito che, con riferimento a tali finalità, gli enti locali trattino dati idonei a rivelare le convinzioni religiose, filosofiche, politiche, sindacali o di altro genere.

Potranno essere effettuati raffronti con dati personali sensibili, detenuti da altre amministrazioni e da gestori di pubblici servizi, anche mediante eventuali interconnessioni; ciò, esclusivamente, ai fini dell'accertamento d'ufficio di stati, qualità e fatti, ovvero del controllo su dichiarazioni sostitutive prodotte dagli interessati (*v. art. 43 d.P.R. 28 dicembre 2000, n. 445*).

I dati utilizzati e le operazioni del trattamento compiute devono risultare indispensabili rispetto alle finalità perseguite

nei singoli casi (*art. 22, comma 3, del Codice*).

6. Iscrizioni ad albi comunali di associazioni ed organizzazioni di volontariato
Taluni comuni hanno rappresentato la necessità di trattare dati sensibili nell'ambito delle competenze che la legge demanda loro per l'iscrizione in albi comunali di associazioni ed organizzazioni di volontariato o per riconoscere titoli abilitativi previsti dalla legge (*art. 68, comma 2, lett. g), del Codice*).

Valutate le circostanze che sono state rappresentate appare lecito che, per lo svolgimento delle predette competenze in relazione alle finalità di rilevante interesse pubblico previste dal Codice, i comuni trattino dati idonei a rivelare lo stato di salute, le opinioni politiche, le convinzioni religiose, filosofiche, di altro genere o sindacali, nonché i dati giudiziari, degli organi rappresentativi delle associazioni e delle organizzazioni di volontariato, ovvero i dati relativi all'adesione di tali associazioni ed organizzazioni ad altre associazioni, organizzazioni o confederazioni a carattere religioso, politico, filosofico, sindacale o di altro genere (*l. 11 agosto 1991, n. 266*).

Sui medesimi dati personali, in conformità alla richiesta di parere, potranno essere effettuate solo le operazioni ordinarie di trattamento menzionate nello schema tipo Anci (raccolta, registrazione, organizzazione, conservazione, consultazione, elaborazione, modificazione, selezione, estrazione, utilizzo, blocco, cancellazione e distruzione).

I dati utilizzati e le operazioni del trattamento compiute devono risultare indispensabili rispetto alle finalità perseguite nei singoli casi (*art. 22, comma 3, del Codice*).

In conclusione, il Garante esprime parere favorevole alle richieste di parere degli enti di cui al menzionato allegato A) a condizione che siano rispettate le predette indicazioni in ordine ai tipi di dati e di operazioni riportate nei punti da 2 a 6, cui le amministrazioni richiedenti sono tenute a conformarsi.

Qualora altri enti locali diversi da quelli di cui all'allegato A), in relazione alla specifica attività svolta, intendano trattare i dati sensibili o giudiziari oggetto del presente provvedimento, essi potranno adottare o integrare i propri atti regolamentari al fine di poter effettuare lecitamente tali trattamenti di dati senza dover chiedere singolarmente all'Autorità il parere ai sensi dell'art. 20, comma 2, del Codice, sempreché il trattamento ipotizzato sia attinente e conforme alle indicazioni fornite con il presente parere.

TUTTO CIÒ PREMESSO IL GARANTE:

1. ai sensi degli artt. 20, comma 2, 21, comma 2, e 154, comma 1, lett. g), del Codice, esprime parere favorevole sugli schemi di regolamento per il trattamento dei dati sensibili e giudiziari delle province, dei comuni e delle comunità montane di cui all'allegato A) in atti, nei limiti delle tipologie di dati sensibili e giudiziari identificati, nonché delle operazioni esequibili, indispensabili per il persequimento delle finalità di rilevante interesse pubblico, a condizione che siano rispettate le indicazioni fornite nei punti da 2 a 6 del presente parere, concernenti le attività in materia di:

a. protezione civile, in relazione al trattamento da parte di comuni e comunità montane delle informazioni idonee a rivelare lo stato di salute di cittadini a fini di programmazione dei piani di emergenza o per dare attuazione, in caso di calamità, a piani di evacuazione;

b. onorificenze e ricompense, in relazione al trattamento da parte di comuni e province di dati idonei a rivelare l'origine razziale ed etnica, le convinzioni religiose, filosofiche o di altro genere, le opinioni politiche, l'adesione a partiti, sindacati, associazioni od organizzazioni a carattere religioso, filosofico, politico o sindacale, patologie attuali o pregresse, nonché i dati giudiziari;

c. agevolazioni tributarie o di utilizzo di fondi per interventi relativi ad edifici di culto, nonché a sedi di partiti ed associazioni, in relazione al trattamento da parte di comuni, in aggiunta a quanto previsto nella scheda 20 dello schema tipo di regolamento per i comuni, anche di dati idonei a rivelare convinzioni religiose, filosofiche, politiche o di altro genere;

d. attività ricreative, di promozione della cultura e dello sport e di occupazione del suolo pubblico, in relazione al trattamento da parte di enti locali di dati idonei a rivelare le convinzioni religiose, filosofiche, politiche, sindacali o di altro genere;
e. iscrizione ad albi comunali di associazioni ed organizzazioni di volontariato in relazione al trattamento da parte di comuni di dati idonei a rivelare lo stato di salute, le opinioni politiche, le convinzioni religiose, filosofiche, di altro genere o sindacali, nonché i dati giudiziari;

2. delibera altresì che gli altri enti locali, diversi da quelli di cui all'allegato A), che in relazione alla specifica attività svolta intendano trattare i dati sensibili o giudiziari oggetto del presente provvedimento, potranno adottare o integrare i propri atti regolamentari al fine di poter lecitamente effettuare tali trattamenti di dati senza dover chiedere singolarmente all'Autorità il parere ai sensi degli artt. 20, comma 2 e 21, comma 2, del Codice, sempreché il trattamento ipotizzato sia attinente e conforme alle indicazioni fornite con il presente parere.

Appendices to Chapter 3

Statement of Informed Consent

Nursing Home Emergency Preparedness Activities

You are asked to participate in this interview on emergency management activities in nursing homes. The interview is part of a study being conducted by the University of Delaware and the Marche Polytechnic University (Italy). The purpose of this study is to improve understanding of emergency preparedness and response of nursing home administrators and healthcare workers in different critical scenarios. Insights will be used to examine the difference between the emergency preparedness activities of US and Italian nursing homes. Interviews will be conducted with a range of nursing home administrators. You have been asked to participate because of your membership in this group. You must be 18 years old or older to participate in the study. There are no anticipated risks associated with this study. The interview will last about 1 hour. The interview will be audiotaped or digitally recorded. The voice files and transcripts will be archived at the University of Delaware's Disaster Research Center on a secured server and may be used for educational or research purposes in the future. Your participation in this study is voluntary and without compensation. You may refuse to answer any specific question raised during the interview. If you wish to withdraw from the study or leave, you may do so at any time before the end of the interview without giving a reason or explanation for doing so. If you do withdraw from the study, this will have no effect on your relationship with the University of Delaware or the other researchers involved. Organizational names will be used in published articles and reports. Confidentiality in this study is not possible owing to 1) the public nature of the project; and 2) the likelihood that officials are familiar to each other, known to other officials in government or in the private sector, and have participated in already-documented activities.

By signing below, you indicated that you:

- understand your rights as a research subject
- understand what the study is about
- voluntarily consent to participate in this study

Your signature:_____

Date: _____

Interview on Emergency Preparedness in Long Term Facilities

A Study conducted by the University of Delaware and the Marche Polytechnic University

Icebreaker questions:

Let me start with matters inside the facility:

1. When you think about emergencies and your nursing home, what is your highest worry?
2. What if anything, are you and other members of the staff doing right now inside your nursing home to ameliorate the emergency-related problems you have identified?
3. What are the most important emergency-related challenges that you and other members of the staff have identified as you have tried to improve the situation inside your nursing home?

Main questions:

4. Did the Post-Katrina Act of 2006 change the way of planning for an inclusive emergency response in your facility? How often do you review or update your emergency plan? How often do you rethink staff preparedness? Do you include people with disabilities in the emergency planning process? Do you ensure people with disabilities a physical and equal access to emergency programs, services and activities within your facility?
5. Currently are there any federal or state regulations that oblige your care facility to address the needs of people with disabilities in emergency situations and to involve them in the emergency planning? Are there any specific federal or state guidelines to create the emergency plan within your care facility? Did you follow them to create the emergency plan?
6. Do the emergency first responders have access to residents' family identity, contact information, health conditions and medication schedule? Do they have access to personal information before a potential event and during the phases of the emergency planning? Do you have experience with the Privacy Rule of HIPPA in emergency situations?
7. Please describe how the emergency plan changed as a result of the Federal Laws on emergency and disability issue. Who was involved in the emergency planning committee? What modifications to the plan did you made? How did the previous and the current extent to training for staff and residents change? Which drills were conducted and under what circumstances, if any, the plan has been implemented?
8. Does the emergency plan include new specific information about the characteristics and needs of the residents? Are they aware of the facility plan? Do residents' families know how and when they will be notified about evacuation plans? Are residents, who are able to participate in their own evacuation, aware of their role and responsibilities in emergency?

9. I am interested in emergency preparedness staffing. What type of training has your medical care staff received in disaster response and evacuation after the events of Hurricane Katrina, Sandy and Irene? Did you implement the training program for medical staff? When was the last time that your staff ran through a practice drill and how often does your facility test the emergency plan?
10. Compared to the past what are your facility's major strengths in terms of emergency management? For example, a well-trained medical staff who works as a team, support from the community and healthcare system, strong facility features (like structure, protected location), good disaster planning.
11. Are there any areas that you would like to improve? What more can be done? For example, increase transportation resources, enhanced education and training programs for medical stuff and patients, need for improved communications systems, more support from State and local governments.
12. Do local first responders (e.g., police, fire department, paramedics and township officials) have a copy of the emergency plan of your Care Facility? Do you have written agreements with them as to who will do what in an emergency? Do you collaborate with external emergency management agencies (State, County, Municipality) to ensure the development of integrated emergency plans?
13. What are the most critical ways the County or State can help care facilities prepare for an emergency situation?

Additional questions

Now let me go more in detail:

14. What are the factors that influence the evacuation or shelter-in-place decision process?
15. To what extent do you believe that staff will remain at work during an emergency, either evacuating or sheltering in place with residents? We would appreciate hearing about accommodations, if any, for families of staff to accompany them during the emergency as well as the extent to which family members are planned for, for example in the amount of supplies on hand.
16. How is information about patients kept and transferred as they leave the facility? For example, are electronic files forwarded to particular individuals? Do hard copy files or wearable flash-drives accompany patients? Please describe the process and how it works.

Intervista agli Amministratori di Istituti di Riabilitazione e Residenze Sanitarie Assistite

Domande introduttive

1. Quando pensa ad un possibile evento calamitoso che potrebbe coinvolgere la sua struttura quali sono le sue maggiori preoccupazioni?
2. Secondo lei in che modo, attualmente, l'organizzazione della sua struttura sta cercando di migliorare le procedure di gestione dell'emergenza?
3. Quali sono le maggiori problematiche che nella sua organizzazione si trova ad affrontare nella pianificazione della gestione delle emergenze? Come si è cercato di risolverle?

Domande centrali

4. In seguito ai recenti eventi calamitosi verificatisi nel nostro Paese (es: alluvioni, terremoti, emergenza neve ecc.) ritiene necessario apportare delle modifiche al piano di gestione delle emergenze della sua struttura? Qualora siano state fatte delle modifiche al piano di emergenza avete riscontrato miglioramenti, ossia queste nuove misure sembrano adeguate a rispondere in maniera più efficace a situazioni emergenziali? Nel piano di emergenza sono state previste procedure specifiche per l'evacuazione delle persone con disabilità presenti nella struttura? Gli ospiti/pazienti della struttura sono stati coinvolti nelle simulazioni delle emergenze e sono stati informati delle procedure da seguire in situazioni emergenziali?
5. La normativa attuale obbliga le strutture assistenziali ad includere nel processo di pianificazione (in fase di definizione dei piani di emergenza) le persone con disabilità? Esistono delle linee guida da seguire per la definizione di un piano di emergenza coinvolgente disabili, e qualora esistessero la vostra struttura ha ritenuto opportuno seguirle?
6. Gli enti esterni preposti alla gestione dell'emergenza (es: Vigili del Fuoco e Protezione Civile) hanno accesso alle informazioni personali degli ospiti della struttura (contatti telefonici e cartella clinica)? Nel caso in cui questi enti non abbiano accesso diretto a tali informazioni (limitazioni per la privacy, ecc.), è presente nella vostra struttura una figura di collegamento con tali enti?
7. Recentemente (anche a seguito degli ultimi eventi calamitosi) quali tipi di simulazione ed esercitazioni sono state condotte? Se no, quando è stata svolta l'ultima esercitazione? Sono state modificate le modalità e periodicità di queste esercitazioni?

8. Quale tipo di formazione teorica e pratica viene erogata al personale medico e paramedico per gestire correttamente le situazioni emergenziali? L'introduzione del Decreto 81/08 ha cambiato le modalità di questa formazione teorico pratica?
9. Rispetto al passato, come si è rafforzata sua struttura nell'ambito della gestione delle emergenze (es: formazione personale, modifiche strutturali alla residenza, un adeguato piano di emergenza)?
10. Quali ritiene possano essere invece le maggiori criticità della sua struttura nell'ottica di una più efficienti gestione delle emergenze (es: implementare i programmi formativi rivolti al personale, migliorare la diffusione delle procedure adottate per la gestione delle emergenze, instaurare un rapporto continuativo di collaborazione con gli enti preposti al primo intervento)?
11. In caso di emergenza, gli enti esterni preposti al primo intervento (Vigili del Fuoco, Croce Rossa, Protezione Civile ecc.) possiedono le informazioni relative al piano di emergenza ed evacuazione della sua struttura? Vengono effettuate simulazioni congiunte con gli enti esterni sopra indicati?
12. Secondo lei in che modo gli enti esterni preposti alla gestione delle emergenze dovrebbero supportare strutture assistenziali come le vostre nella pianificazione e gestione di situazioni emergenziali?

Domande di approfondimento

13. Quali sono i fattori che influenzano o che hanno influenzato il processo decisionale relativo ad un'eventuale evacuazione delle persone presenti nella sua struttura?
14. In caso di emergenza, si aspetta che il personale rimanga in servizio applicando le procedure previste in tali situazioni? La struttura è preparata in caso di necessità ad assistere sia i degenti che le altre persone a qualsiasi titolo presenti all'interno della residenza (beni di prima necessità, ospitalità ecc.)?
15. Come è possibile trasferire a terzi prenditori in carico del degente le informazioni presenti nella cartella clinica in caso di emergenza? Esistono ad esempio copie elettroniche dei dati presenti nella cartella clinica?

Survey on emergency preparedness in long term facilities

Statement of informed consent

You are asked to participate in this survey on emergency management activities in nursing homes. The survey is part of a study being conducted by the University of Delaware and the Marche Polytechnic University (Italy). The purpose of this study is to improve understanding of emergency preparedness and response of nursing homes in different critical scenarios. Insights will be used to examine the difference between the emergency preparedness of the US and Italian nursing homes.
Survey will be conducted with a range of nursing home staff. You have been asked to participate because of your membership in this group. You must be 18 years old or older to participate in the study. There are no anticipated risks associated with this study. The survey to the nursing home staff will last about 20 minutes. The survey will be digitally recorded. The voice files and transcripts will be archived at the University of Delaware's Disaster Research Center on a secured server and may be used for educational or research purposes in the future.Your participation in this study is voluntary and without compensation. You may refuse to answer any specific question raised during the survey. If you wish to withdraw from the study or leave, you may do so at any time before the end of the survey without giving a reason or explanation for doing so. If you do withdraw from the study, this will have no effect on your relationship with the University of Delaware or the other researchers involved.

Participant name _____

Participant signature _____

Survey Questions:

Demographic Information

Age: _____ years

Gender: □ Male □ Female

Area of specialization:

Years of employment in this facility: _____ years

1. Our emergency plan gives practical guidance on managing an emergency:

Strongly Disagree	Disagree	Neither	Agree	Strongly Agree

2. I receive sufficient training to respond to an emergency:

Strongly Disagree	Disagree	Neither	Agree	Strongly Agree

3. How often do you run through the following drills?

   - Fire drill: □ Monthly □ Quarterly □ Annually □ Other: specify……
   - Hurricane: □ Monthly □ Quarterly □ Annually □ Other: specify…….
   - Winter storm: □ Monthly □ Quarterly □ Annually □ Other: specify…….
   - Other: □ Monthly □ Quarterly □ Annually □ Other: specify…….

4. Basic and continuing training improves understanding emergency response:

Strongly Disagree	Disagree	Neither	Agree	Strongly Agree

5. Care facilities have improved the way nursing home staff is prepared for an emergency

Strongly Disagree	Disagree	Neither	Agree	Strongly Agree

6. I feel more involved in the emergency planning activities of my facility

Strongly Disagree	Disagree	Neither	Agree	Strongly Agree

Questions addressed to medical and paramedical staff:

7. Planning is critical for evacuation, reception and provision of care to residents:

Strongly Disagree	Disagree	Neither	Agree	Strongly Agree

8. Practical experience in providing care in emergency help me to facilitate care to residents:

Strongly Disagree	Disagree	Neither	Agree	Strongly Agree

Questionario relativo al progetto di dottorato su

"Emergenza e Disabilità"

(Università Politecnica delle Marche e Istituto Santo Stefano Riabilitazione)

Dati Anagrafici:

Età:_____ anni

Sesso: □ M □ F

Qualifica e Mansione:_____

Anzianità di servizio nell'attuale struttura:_____ anni

1. Il piano di emergenza della struttura in cui lavoro fornisce indicazioni pratiche su come affrontare situazioni di emergenza:

Fortemente in disaccordo	In disaccordo	Né l'uno né l'altro	D'accordo	Molto d'accordo

2. Ritengo di aver ricevuto sufficiente formazione per affrontare situazioni di emergenza:

Fortemente in disaccordo	In disaccordo	Né l'uno né l'altro	D'accordo	Molto d'accordo

3. Quanto spesso hai preso parte alle seguenti esercitazioni di emergenza?

   - Antincendio: □ Mensili □ Semestrali □ Annuali Altro: specifica……..
   - Sicurezza sismica: □ Mensili □ Semestrali □ Annuali Altro: specifica…….
   - Emergenze neve: □ Mensili □ Semestrali □ Annuali Altro: specifica……..
   - Altri tipi di emergenze: □ Mensili □ Semestrali □ Annuali Altro: specifica…….

4. Ritengo che una formazione continua possa aumentare la mia capacità di affrontare situazioni emergenziali:

Fortemente in disaccordo	In disaccordo	Né l'uno né l'altro	D'accordo	Molto d'accordo

5. Ritengo che nella struttura in cui lavoro la preparazione del personale nell'affrontare possibili eventi emergenziali stia migliorando:

Fortemente in disaccordo	In disaccordo	Ne l'uno né l'altro	D'accordo	Molto d'accordo

6. Mi sento coinvolto nelle attività di pianificazione dell'emergenza svolte all'interno della struttura in cui lavoro:

Fortemente in disaccordo	In disaccordo	Né l'uno né l'altro	D'accordo	Molto d'accordo

Domande rivolte solo al personale sanitario e agli operatori socio-sanitari:

7. Ritengo che una efficace pianificazione aiuti ad affrontare meglio le procedure di evacuazione e di assistenza in caso di eventi calamitosi sia nei confronti dei pazienti ricoverati che di quelli provenienti da altre strutture sul territorio:

Fortemente in disaccordo	In disaccordo	Né l'uno né l'altro	D'accordo	Molto d'accordo

8. Le esercitazioni di emergenza possono migliorare la mia capacità di assistere i pazienti in situazioni emergenziali

Fortemente in disaccordo	In disaccordo	Né l'uno né l'altro	D'accordo	Molto d'accordo

RESEARCH OFFICE

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DATE: March 9, 2014

TO: BEATRICE GATTO
FROM: University of Delaware IRB

STUDY TITLE: [575319-2] EMERGENCY PREPAREDNESS IN LONG TERM FACILITIES

SUBMISSION TYPE: Amendment/Modification

ACTION: APPROVED
APPROVAL DATE: March 9, 2014
EXPIRATION DATE: February 20, 2015
REVIEW TYPE: Expedited Review

Thank you for your submission of Amendment/Modification materials for this research study. The University of Delaware IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the study and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the study via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the signed consent document.

Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure.

All SERIOUS and UNEXPECTED adverse events must be reported to this office. Please use the appropriate adverse event forms for this procedure. All sponsor reporting requirements should also be followed.

Please report all NON-COMPLIANCE issues or COMPLAINTS regarding this study to this office.

Please note that all research records must be retained for a minimum of three years.

Based on the risks, this project requires Continuing Review by this office on an annual basis. Please use the appropriate renewal forms for this procedure.