

# **Planned Power Outages and Children and Adults with Disabilities who require Medical Care: Looking at the Example of the 2011 Touhoku Earthquake and Tsunami**

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## 1. Introduction

The Touhoku earthquake occurred on March 11th, 2011. The area around Tokyo was shaken by a powerful earthquake (“shindou 5 - strong” on the Japanese earthquake scale) at 14:46. Trains stopped running, and the streets were filled with confused people with no way to get home. On the following day, March 12th, TEPCO (Tokyo Electric Power Company) announced the implementation of “rolling blackout” [1] stoppages in power provision to the capital area beginning the following Monday, March 14th, in response to fears of power shortages resulting from damage to nuclear power plants and other facilities caused by the disaster. “Rolling blackouts” were reported as “scheduled blackouts” in the media, but the specifics of exactly when each area would lose power were not known until just beforehand, and people with disabilities requiring medical care living in the capital area were placed in an extremely precarious position. If the blackouts made it impossible for them to secure a source of electricity for their mechanical ventilators and suction machines their lives would be in danger. The circumstances that arose as a result of this disaster and the ensuing planned blackouts forced many people with disabilities who live at home and rely on electrically-powered medical devices such as ventilators and suction machines to confront the serious issue of what they should do to protect their lives and maintain their ability to live in their own homes when a disaster or blackout occurs.

In the end they somehow found ways to get through the three-hour scheduled blackouts, in some areas no blackouts were implemented, and the summer ended without any of the large-scale power outages that had been predicted. Compared to

the severe conditions faced by disaster victims with disabilities far away in the Touhoku area, the conditions endured by people with disabilities in the area around the capital may have become buried as memories of that time fade. For this very reason, however, I thought it was important to document them.

The most notable effect felt in the capital area as a result of the Touhoku earthquake was the implementation of scheduled blackouts necessitated by the nuclear power plant accident which put the lives of people with disabilities who require medical care utilizing electrically-powered medical devices in danger. In the capital area many people with disabilities who require medical care live at home. In this paper I will document the circumstances people with disabilities who require medical care encountered in the capital area as a result of the Touhoku earthquake, and raise the issue of the government's grasp of these circumstances not being adequate for the construction of effective policy responses to planned blackouts and the confirmation of the safety of these individuals.

## 2. Circumstances at the time of the disaster

Interviews were conducted with four mothers of children with severe disabilities who require medical care with whom the author has been involved living in Nakano City, Tokyo Metropolitan Area. The participants were interviewed individually in their homes or in a cafe. Scheduled Blackouts were ultimately never implemented in Nakano City, so a group interview of three people with disabilities using mechanical ventilators and residing in Saitama Prefecture, an area in which scheduled blackouts were implemented, was conducted in July in the offices of an independent living center in Saitama City.

### 2-1. Helpers and home-visit nurses moved to confirm the patients' safety and provide support

Of the four mothers interviewed, three of their children had just arrived home from school or a daycare facility. All three ordinarily utilized home care or home nursing services. When the earthquake occurred, a helper had just arrived at the home of Ms. C to assist with bathing. Immediately after the earthquake a home-visit nurse and a helper were at the home of Ms. A, a helper was at the home of Ms. B, and a home-visit nurse and physical therapist were at the home of Ms. C.

Ms. A describes being glad that the home-care nurse and helper did not cancel their appointments as follows:

The home-visit nurse arrived a bit late at just after three (in the afternoon). The building's elevator was stopped, so the nurse came up the emergency stairs. The elevator remained out of service for the next three days. I discussed how to respond to an evacuation with the nurse, and piled injection equipment, three days' worth of medication, a thermometer, diapers, medical cards/examination cards, one day's worth of regular-use Racol, a suction machine set, and a saturation monitor (a device that measures oxygen saturation) on a wheelchair so that I would be able to get away quickly. If I had been by myself I think I would have panicked and had no idea what to do. The home-visit nurse left to check on all of his other patients. The second aftershock occurred, and the helper arrived a bit early at five thirty in the evening. She came thinking our family might be in danger. I couldn't reach my husband, so the helper stayed. I had her spend the night. The streets outside were densely packed with people and cars. My child's symptoms grew severe, and the helper responded by administering a suppository. My husband arrived home at three in the morning after having walked from Chiba.

Ms. B also relates how a helper came and assisted her:

The home-visit helper arrived at just past three (in the afternoon). My child uses concentrated oxygen (electrically powered, fixed-type) at home and carries two oxygen canisters (one small and one large with a total capacity of 0.5L; enough for 12 hours) when he goes out. Because the helper had come, when the aftershocks occurred we were able to exit from the second floor carrying the canisters and come back inside [when the shaking had stopped]. In order to be ready to evacuate at any time we put together a large pack containing three or four days' worth of medical supplies, medication, oxygen canisters, diapers, etc. Even with my husband we would need my mother's help [to carry everything] and I was so worried about who would carry my child if we had to get away that I hardly slept at night.

Saying that he would check on his other patients, the home-visit nurse who had come to Ms. A's house then left and went to the home of Ms. C. Ms. C describes her experience as follows:

The home-visit nurse was not scheduled to visit on March 11th, but he came anyway. He had actually come to the nearby home of Ms. A, but he stopped by to make sure that my child was OK before going home. I was very glad he came.

There were home-visit nurses who took it upon themselves to go and check on the safety of the people to whom they normally provided care. In some cases the home-visit nurses and helpers moved immediately to provide support and check on the safety of those they normally visited when the disaster occurred. The fact that home-visit nurses and helpers come to their homes gave these mothers a strong sense of security. While this earthquake happened to occur at exactly the time these care providers normally visit, helpers and home-visit nurses played an important role in confirming safety and providing support when the natural disaster struck. A response that goes beyond normal working hours, like that of the helper who spent the night in the home of Ms. A, is required when a natural disaster occurs. However, as is described in the following section, this kind of response on the part of helpers during a disaster is not acknowledged as part of their job. When a disaster occurs, the fastest confirmation of safety and provision of support to people with severe disabilities is provided by the helpers and home-visit nurses who normally assist them. There is a need to reform the current system so that helpers and home-visit nurses can perform this confirmation of safety and provision of care during a disaster as part of their formal duties.

2-2. A system to dispatch helpers and other personnel capable of responding when a disaster occurs is needed

Mr. H, a person with a severe disability who runs a helper agency in Nakano City, said the following about the activities of helpers after the March 11th earthquake:

Helpers/full-time workers/part-time workers at the helper agency each did their part, going by bicycle to confirm the safety [of those receiving the agency's services]. It was very difficult; furniture had fallen over in the homes of care recipients making it impossible for them to enter in their wheelchairs, and plans had to be made to have them sleep crowded together in the office or at the home of a friend. In addition, as a result of the planned blackouts, the dispatching of staff for this purpose had to be arranged without knowing how long it would take helpers who live far away to arrive and return home. We also, of course, had to do our normal

work. We could not allow holes to appear in our operations. (Sora tobu kurumaisu toraberusaron 2011 [Wheelchair flying in the sky travel salon 2011])

Confirming safety in the event of a disaster has not been designated as the job of helpers and home-visit nurses. As in the above examples, however, there were cases in which they immediately moved to confirm the safety of those to whom they provided care independently. The helper who spent the night at the home of Ms. A did so of her own volition to alleviate Ms. A's anxiety. There has been no systematic determination, however, of how to manage the working time of helpers during an emergency. When an emergency such as a natural disaster occurs and helpers are placed in a situation in which they have no choice but to continue to provide care, the issue of what to do about these extended hours and their cost has yet to be resolved. Moreover, nursing care benefits cannot be obtained for time spent going to the homes of care recipients to confirm their safety.

When this earthquake occurred, the Ministry of Health, Labour and Welfare released notification [2] of a flexible response concerning caregiver hours at the discretion of local authorities. There were cases, however, in which problems arose when helpers fled the disaster areas with those receiving care and the local authorities did not accept care time being exceeded. [3] It is necessary for the national government to not only request a flexible response on the part of local authorities but also to put in place a system to manage the dispatching of helpers and other caregivers in the case of a disaster, including taking budgetary measures and providing needed caregiver hours during special circumstances such as an evacuation and providing nursing care benefits to cover the work of confirming safety when a disaster occurs.

### 3. The response of people with disabilities who require medical care to planned blackouts

Facing a power shortage caused by nuclear power plants being shut down after the earthquake, on March 12th, the day after the disaster, TEPCO announced that it would be dividing the region into blocks and implementing planned blackouts in each block in turn according to a fixed schedule (rolling blackouts). The duration of each blackout was to be three hours. The blackout areas kept changing right up until the outages started, however, and the resultant blackouts could hardly be described as "planned." People with disabilities who require medical care using devices that need electricity living in the areas designated to undergo blackouts were in a state of extreme anxiety. What

follows is a record of the circumstances at that time according to the statements of those directly involved.

### 3-1. ALS patients [4]

These patients are attached to a mechanical ventilator twenty-four hours a day, so for them a power outage is life-threatening. Immediately after scheduled blackouts were announced, the author visited the homes of ALS patients in Nakano City where she lives.

#### \*ALS patient K

His ventilator had a battery that seemed capable of lasting for eight hours. His suction machine, however, used a plug, and his backup suction machine was old so he didn't know if the battery would work or not. His family called TEPCO's customer center and requested the loan of a generator. It seems that they did this because TEPCO's website said they would respond to requests for loan generators. TEPCO's response, however, was that they could not provide a generator and that patient K's family should contact their local authorities. Mr. K's family then telephoned Nakano City, but it seems that they too were not responding to requests for things like loan of generators.

#### \*ALS patient L

When I visited the home of Ms. L on March 14th, the public health nurse had just come to see her. The helper was also there, and everyone was thinking about what they should do when the planned blackout occurred. The mechanical ventilator's battery would last for eight hours, but their problem was that they did not know whether or not the suction machine would last three hours. So together they thought up and tested other methods to use if the suction machine's battery failed, such as using tools like syringes to suck out phlegm.

#### \*ALS patient M

Many batteries had been prepared in advance at Mr. M's house, and the ventilator and the suction machine would both have power even if a blackout lasted eight hours. There was a shortage of helpers, however, and for some periods of time the only caregiver was Mr. M's wife. If an earthquake happened during one of these periods, it would be impossible for them to flee, so his wife said that if the house came down, it would be the end of them.

## 2-2. People with disabilities who require medical care

In their interviews the mothers of children with disabilities who require medical care living at home in Nakano City introduced in section 2.1 responded as follows regarding the response to scheduled blackouts:

\*Ms. B

Five days after [the earthquake], I went to the hospital where my child normally receives care and asked what I should do about oxygen. The doctor at the hospital suggested I find a family doctor in my neighborhood. The doctor wasn't sure about hospitalization, but oxygen could be loaned out. The hospital was located in a scheduled blackout area, however, so I was told that in the event of a blackout the situation would be the same. It was suggested that I consult the medical association after confirming whether or not the local authorities could respond to my needs. After consulting with the medical association I was referred to Dr. O, so I visited this physician. It was decided that my child would see the doctor once a month. I was told that Dr. O would talk to other doctors and have a local physician procure oxygen, but I don't know what happened after this. When the city checked on me, I did not have batteries but had been able to obtain a battery-powered nebulizer. Regarding suction and inhalation my child would be fine if there were a three hour blackout. My worry was oxygen. I had five large and five small spare oxygen canisters in my home, but they would be empty in a week. I had someone come and exchange them every week, but if the blackout occurred just before they were empty it would be a problem. There were also cases in which the oxygen provider did not have oxygen. I was worried about what to do during the night. My child's body temperature regulation is not good, so she sweats easily. There was a danger of dehydration because she normally uses an air conditioner and humidifier twenty-four hours a day.

\*Ms. C

I wondered what to do about my child's ventilator and suction machine. I didn't know what would happen if there were a scheduled blackout. If there were only blackouts between certain times I would find a way to endure them. But what was I to do if the blackouts happened without advance warning? With this kind of problem in mind I had contacted TEPCO twice before the earthquake occurred to ask for a generator, but both times I had been told to prepare one myself.

Generators cost ¥200,000 so I couldn't just go out and buy one, and even if I had had the money I didn't know what kind would be good, so when the earthquake happened I hadn't been able to procure a power source. Fortunately, my father was able to make a battery device capable of lasting two to three hours. I didn't actually use it but having it gave me piece of mind. If something happened I would have no choice but to flee to the hospital, so I thought I had better have a ventilator and several days worth of suction equipment in my home. At the time I had two or three batteries for my suction machine, each of which could be used for about a day, so I could have used it for two days without power. I wasn't terribly worried because I thought I could bring my child to the hospital on foot. My child only used the ventilator at night, but since it had no internal battery I was a bit concerned.

\*Ms. D

My child was being hospitalized at the time of earthquake, and an announcement was broadcast saying that there would likely be scheduled blackouts but there was no need to worry because the hospital had its own generators. I was relieved to be told that while patients from Fukushima were being accepted and my child was not able to continue hospitalization, if worst came to worst we can come to the hospital. Regarding suction machines (used once per hour), I had one plug-in and four battery-powered devices. I also had a manual suction device. My child uses oxygen at night for approximately eight hours while sleeping. On the day after the earthquake I received phone calls from both my child's school and oxygen provider. There were no problems with the inhalation machine because it was battery-powered. My child would be fine if there were planned blackouts lasting three hours.

3-3. People with disabilities who use mechanical ventilators and live in areas in which planned blackouts were implemented

A group interview of three people with disabilities who use mechanical ventilators was conducted on July 7th at an independent living center in Saitama City. They described their circumstances during the scheduled blackouts as follows:

\*Ms. E (Resident of Saitama City)

When the earthquake occurred, I was in my home on the first floor of an apartment building. Together with my helper I fled to an evacuation point located in the



parking lot of a factory, but it was impossible to find a power source for my ventilator there so I went to the office of an independent living center to secure access to electricity. I experienced planned blackouts five times beginning March 20th. Every day the timing was different, and the blackouts lasted about three hours. They were unplanned blackouts in the sense that you didn't know what time they were going to occur until the night before. My ventilator's internal battery lasts for eight hours, and it takes about four hours to charge. This time the blackouts were only three hours long, so there was no problem, but if there were blackouts that lasted longer than eight hours I think I would have to be transported by ambulance to the hospital I am to go to in an emergency. After this earthquake this hospital received patients from Ishinomaki City, however, and since during a disaster power will be used for severely injured patients, I might not be able to receive treatment. In this sort of situation I want the government to do something. As a ventilator user, I received a telephone call from the city, but I was not asked any questions about securing a source of power. I asked them if there were emergency power supplies but I was told there weren't any.

\*Mr. F (Resident of Kawaguchi City)

I am an employee of an independent living center, and on the day of the earthquake I was doing work as usual. I fled outside after the second tremor. I normally plug my ventilator into a wall socket in the office, so I could not take it with me. I exited to a nearby parking lot and was able to secure power for my ventilator through a car's cigarette lighter, so I spent the next hour drawing power from the car while waiting to see what would happen as the aftershocks continued. The planned blackouts came as close as fifteen meters to my house.

\*Ms. G (Resident of Kawaguchi City)

Kawaguchi City experienced planned blackouts, but by chance the area in which both my and Mr. F's homes are located was exempted. My ventilator's internal battery only lasts for thirty minutes. The external battery I bought with my own money lasts ten hours. In preparation for the planned blackouts some of my family members drove to my house and stayed overnight, and it was then possible to get power from their car. As long as there is gasoline electricity can be taken from a running car. My ventilator would be fine if there were planned blackouts lasting three hours. The situation concerning my suction machine, however, was worrying. I was also worried about how to secure power if the blackouts continued to occur.

TEPCO announced on its website that it would be lending out generators, but they were only thinking about lending generators to hospitals and other institutions and had not thought about lending them to individuals in their homes. Somewhere nearby that will lend generators to people using mechanical ventilators when a blackout occurs is needed.

From the above interviews, it is clear that these individuals worried about not having a suction machine. There is a need for local government support measures such as preparing locations close to users' homes where they can borrow generators or external batteries and making it possible for individuals to obtain reserve batteries.

#### 4. Local authorities' response to prepare for blackouts

##### 4-1. Local authorities' response to prepare for planned blackouts

On March 13th, a notification entitled "regarding the informing of public health centers concerning alerting people receiving care in their homes using devices such as mechanical ventilators about rolling blackouts implemented by TEPCO" was sent to local authorities by the Ministry of Health, Labour and Welfare. The author requested that Nakano City send public health nurses to the homes of people using medical devices before the planned blackouts began to determine whether or not they were prepared for power outages. Nakano City received the notification from the Ministry of Health, Labour and Welfare and confirmed the state of use of medical devices and response in the case of a blackout through visits and telephone calls between the 14th and 18th of March. For children under eighteen years of age this survey was carried out by the city's child and child-rearing department child and child-rearing support center, for people over the age of eighteen with an intractable disease patient it was carried out by the health and welfare department health and welfare support center, and for people over the age of eighteen with a disability it was carried out by the health and welfare department disability welfare section. The results of this investigation were that among children under eighteen years of age, apart from three cases in which reserve suction machines had not been prepared, all of the individuals in question seemed to be in circumstances in which they could handle three hour blackouts. In the cases in which reserve suction machines had not been prepared, it was not the case that measures to address the situation were being taken; the family was simply told to obtain reserve devices themselves. And since the family of Ms. D, whose child was being hospitalized, was not contacted by the city, it seems that not all families were contacted. This

undertaking did, however, lead to Nakano City having a better understanding of the circumstances of people living at home who require medical care.

Nakano City also mailed a notice “regarding the response to shortages of power provided by TEPCO” to people using medical devices in their homes, urging them to prepare for blackouts by readying reserve devices and backup power sources on their own, consult with their local authorities and home visit nurses, always keep their medical device batteries charged, make sure a resuscitation bag is ready to be used at any time, and prepare rechargeable, foot-operated and hand-operated suction machines in addition to an installed device. The notification from the Ministry of Health, Labour and Welfare was an alert concerning planned blackouts, and was not a document urging local authorities to implement measures in response. Local authorities thus did not prepare a response for when blackouts occurred. As will be described in section 2 below, however, there are limits to how people can respond on their own as individuals. There is a need for assistance measures to be implemented by local authorities.

Using a supplementary budget adopted in June of 2011 for measures to deal with the disaster, based on the results of this survey Nakano City installed manual suction machines and manual respiration assistance devices at a daycare facility attended by children with disabilities who require medical care and two care centers utilized by adults with disabilities who require medical care to be used when power outages occur. [5] This can be viewed as a result of the survey of preparedness for scheduled blackouts. Policies cannot be created without an understanding of the facts on the ground. It is therefore important for local authorities to develop this kind of understanding.

#### 4-2. Batteries and generators are needed when blackouts occur

When a blackout occurs, what is important for people with disabilities who require medical care is securing a source of power for their medical devices. Securing power sources was identified as a major problem in the interviews conducted with members of the independent living center in Saitama City, an area in which blackouts actually occurred. Members of the independent living center requested measures to supply them with power from the city’s disaster response division (they had been told they could not be provided by the disability welfare division), and subsequently emergency generators were set up in a community center in the City’s Chuo Ward. However, since generators produce higher voltages than the 100V sockets mechanical ventilators are connected to in users’ homes, there were concerns that ventilators could break down if connected to a generator. None of the members had ever used a generator. They did not know whether

or not they would actually be able to use one to power their devices.

It seems that Ms. E telephoned her ventilator's manufacturer to see if they would loan out batteries from their stock. Their response was that they would not. Each battery apparently costs ¥40,000 and only lasts for ten hours. "There is no government assistance, so [batteries] are too expensive for people to buy for themselves and people who don't have a lot of money can only use plug-in power," said Ms. E. Her ventilator is leased but there is no government support for external batteries, which must be paid for entirely by the user, and including replacements this has reportedly cost her a total of ¥400,000 so far. Why is there no government support for the purchase of batteries, a necessary piece of equipment? Ms. E speculated that "it was originally assumed that people using ventilators would not go outside. It was assumed that they would stay in their homes connected to ventilators designed to be plugged into a wall socket." Mr. F said, "going out connected to an external battery is a luxury, so assistance is not provided." Ms. E said, "even a person with a disability who cannot go out and spends all of their time at home in bed needs an external battery when this kind of disaster occurs, so the government should assist in procuring external batteries." I agree with her assertion.

After the disaster, Ms. A, the mother of a child with a disability, looked for a reserve battery on the Internet, but affordable batteries were sold out and she was thus unable to obtain one. She wishes there had been information on where batteries and generators could be found and a system that provided assistance in purchasing reserve batteries to allow people who use medical devices at home to prepare for blackouts. Ms. A later purchased an uninterruptible power device to secure a source of power for her child's medical devices.

During a blackout wall-socket power cannot be used, so a battery or generator is needed. Generators like those kept in disaster management warehouses, however, cannot be used in densely populated residential districts or apartment buildings in urban areas. Their noise and smell cause problems for neighbors, and they worsen the condition of the people using them. As is done in Saitama City, it is better to set up generators at public facilities and provide power to evacuees who require electricity for medical or other devices. The best solution is for the government to assist individuals in procuring a stockpile of batteries. As was expressed in the group interview, while batteries are essential items they are too expensive for individuals to buy on their own and no assistance is provided by the government. The government must enact policies, such as funds to allow each individual to purchase at least one spare battery and battery installation assistance for every person with a disability who requires medical

care, to make sure that everyone who needs reserve batteries can obtain them.

In June Tokyo Metropolis conducted a survey concerning the blackout preparations of people who use mechanical ventilators in their homes. After receiving the results [6], on July 15th the government implemented an “emergency assistance for people receiving treatment at home” support system to provide assistance for things such as external batteries. The purpose of this system was to prepare for circumstances such as large scale blackouts and ensure the safety of people using mechanical ventilators in their homes. Its target was medical institutions providing mechanical ventilation treatment to patients receiving medical care in their homes. These institutions were notified about this system directly, but the Nakano City welfare office did not hear about it. Because measures to support people with disabilities requiring medical care are carried out with a focus on medical institutions, it is difficult for local authority welfare offices to obtain a clear understanding of the state of affairs concerning these individuals.

## 5. The issue of a system to confirm safety

5-1. An adequate understanding of the circumstances of people with disabilities who require medical care has not been obtained

At the time of the Great Hanshin earthquake, too, and during the Touhoku earthquake, a barrier encountered when rescuing people with disabilities in the affected region was the problem of not knowing where they were and not being able to obtain any information from the government. Aid for people with disabilities who require medical care living at home was urgently required but without knowing their location the state of affairs was such that even distribution of aid such as medical supplies could not be carried out. I think the government’s lack of understanding of the circumstances of people with disabilities who require medical care may well have impeded both the confirmation of their safety and the provision of support not only in the Touhoku area directly affected by the disaster but in the area around the capital as well.

In “Concerning comprehensive support for people with severe disabilities - Results of a survey conducted in Kyoto City, Fukuoka City, Nakano City, and Morioka City” (Sato 2009), the author found that, according to the results of a survey conducted in four municipalities, the number of people receiving medical care was not known in Kyoto City, Fukuoka City, and Morioka City.

In Nakano City each department was surveyed (children under eighteen, adults over eighteen, and people with intractable disease patient are handled by the child and

child-rearing division, the disability welfare section and health and welfare center respectively), and the results showed a total of seventy severely disabled people, among whom thirty-nine required medical care (six in institutions). Considering the fact that in Nakano City the majority of people receiving medical care live at home, confirming their safety when a disaster occurs is extremely important.

For people with disabilities who require medical care, evacuation is impossible if they have only one family member because there is too much to carry. They also face a life-threatening situation if there is a power outage. For these reasons it is necessary for the government to ensure it has a sufficient understanding of the circumstances of people with disabilities who require medical care and establish a system that can rapidly confirm the safety of these individuals when a disaster occurs.

#### 5-2. A system for registering people who require assistance in the event of a disaster

After the Great Hanshin earthquake in 1995, confirming the safety of people who require assistance, such as elderly people and people with disabilities, was a major problem, and the number of local authorities creating systems to register people who need assistance in the case of a disaster increased. According to the “survey of the state of measures to address people who require assistance in the case of a disaster” conducted by AJU Independence House [7] in fiscal 2008 targeting the four prefectures in the Tokai area (Aichi, Gifu, Mie, and Shizuoka), over 90% of local authorities had completed, were in the process of creating, or were planning to create a list of people who require assistance for a system of registering people who need assistance in the case of a disaster. We will have to wait for future studies to determine whether or not systems to register people who require assistance in the case of a disaster functioned after the Tohoku earthquake, but such systems existed in areas affected by this disaster such as Kamaishi City, Ishinomaki City and Iwaki City.

In Nakano City, too, there is a “Nakano City system for the registration of people who desire assistance in the event of an extraordinary disaster.” A pilot program for this system was initiated in 1989, before the Great Hanshin earthquake, and the system began functioning in earnest in 1992. The system covers people over the age of sixty-five, people with disabilities, and people with recognized intractable disease patient who would have difficulty evacuating by themselves. These individuals submit their address, name, date of birth, contact information, and physical condition to the city. The list of registered names is distributed to local voluntary organization for disaster prevention, local city centers, and police and fire departments, and these organs are supposed to act

to confirm the safety of the individuals in question and provide assistance in the event of a disaster. The meaning of this system is to confirm the safety of people with disabilities and provide assistance in the event of a disaster. However, this Nakano City system, which was established quite early from a national perspective, did not function after the 2011 earthquake.

### 5-3. Systems for registering people who require assistance in the event of a disaster that did not function

I asked the four mothers of children with disabilities mentioned above whether or not their safety had been confirmed.

#### \*Ms. A

I received a telephone call from a welfare commissioner on March 14th, and was visited by a welfare commissioner and two child welfare commissioners on March 30th. Although I had registered with the city's system for the registration of people who desire assistance in the event of an extraordinary disaster, the city did not pass on my information to the head of the local voluntary organization for disaster prevention.

#### \*Ms. B

Although I had registered with the city's system for the registration of people who desire assistance in the event of an extraordinary disaster, I did not even receive a single telephone call. No one visited me and I wondered if there was any point in having registered.

#### \*Ms. C

I received a telephone call from a welfare commissioner around the middle of April. I have not yet been contacted by the local voluntary organization for disaster prevention.

I had registered with the system for the registration of people who desire assistance in the event of an extraordinary disaster but nothing came of it. I had registered with the disaster management department, so I contacted them at the beginning of April to ask about what was being done. It was told to me that the person in the disaster management department asked the local voluntary organization for disaster prevention for visit to registrants.

\*Ms. D

Nobody from the local voluntary organization for disaster prevention came. I have put up a registered person who requires assistance sticker, and I hope someone will check on me after things have calmed down a bit.

As these statements make clear, none of the people interviewed were checked on by the local voluntary organization for disaster prevention through this registration system. While a system for the registration of people who desire assistance in the event of an extraordinary disaster had been put in place, it did not function after this disaster. When I asked the person in charge of the Nakano City disaster management section in June why the system had not functioned, I was told it was because it had not been determined how severe an earthquake had to be to trigger the confirmation of the safety of those who had registered. In a response to this disaster, it seems it has now been decided that in future the local voluntary organization for disaster prevention will take action to confirm the safety of registrants in the event of a “shindo level 5 - strong” or higher earthquake. For reasons related to the protection of personal information, however, the list of names of those requiring assistance has only been given to the head of the local voluntary organization for disaster prevention. The head of the local voluntary organization for disaster prevention and many of the members of the local voluntary organization for disaster prevention and neighborhood association are of advanced age. In practice, it is not possible for the elderly head of the local voluntary organization for disaster prevention to go around and confirm the safety of those requiring assistance. To whom the head of the local voluntary organization for disaster prevention gives the list of names and how the confirmation of safety is to be carried out has been left up to the local voluntary organization for disaster prevention, and this process remains unclear. An employee of the city has said that expressions of doubt about whether the local voluntary organization for disaster prevention can provide assistance to those who require it have been received from members of the local voluntary organization for disaster prevention. There is uncertainty about whether the system for the registration of people who desire assistance in the event of an extraordinary disaster is really a system capable of functioning when needed.

The local voluntary organization for disaster prevention did not visit to confirm safety, but some welfare commissioners did conduct safety checks via telephone and home visits. The welfare commissioners’ responses differed widely; one telephoned after



three days, one visited after one month had passed, and some did not make contact at all. This was because checking on the safety of people with disabilities after a disaster is not designated as part of a welfare commissioner's duties, and while an elderly person living alone had a list of names of people with disabilities, this list was not possessed by welfare commissioners. People who made contact and welfare commissioners who visited people's homes can be seen as having contacted the homes of people with disabilities known to them on their own initiative.

After the 2004 Chuetsu earthquake, Kashiwazaki City in Niigata Prefecture registered people who require assistance using a system in which the names of two people requiring assistance were registered to one local care provider, and when the 2007 Chuetsu offshore earthquake occurred this system allowed the confirmation of safety and provision of guidance in the Kitajo district of Kashiwazaki City to go smoothly. In Kanagawa Prefecture's Chigasaki City, confirmation of the safety of people who require assistance was conducted after the Touhoku earthquake, and it appears that 76.2% of those registered were checked on. It seems that Chigasaki City was able to conduct safety confirmation after this disaster because a system of safety confirmation by local comprehensive support centers in addition to welfare commissioners and local voluntary organization for disaster prevention had been put in place. I think the creation of systems for confirming the safety of people who require assistance through this kind of multi-layered network is needed. It is also necessary to examine how local authorities' systems for registering people who require assistance in the event of a disaster operated after this earthquake and consider policies to improve them.

In order to provide local mutual assistance, not only when disasters occur but on a regular, everyday basis, in 2011 Nakano City began creating a local mutual assistance network. On the basis of newly established "regulations concerning the promotion of local mutual assistance activities," a list was compiled of people over the age of seventy living alone, households of residents over seventy-five years of age, and people with disabilities who wanted to be registered, and this list was then given to the desired neighborhood association to facilitate regular checks on the registrants. Whether or not it will function effectively is a question to be addressed later on. Another issue to be addressed is the relationship between this system and the Nakano City system for the registration of people who desire assistance in the event of an extraordinary disaster. I require this local mutual assistance system designed to check up on registrants on a regular basis and not only when there is a disaster to function effectively as part of a

multi-layered network serving the needs of people with disabilities who require medical care.

## 6. Discussion

According to interviews conducted with people with disabilities who require medical care and their parents living in Nakano City, Saitama City, and Kawaguchi City in the Tokyo area, it became clear that what is particularly important to these individuals is confirmation of safety and measures to address planned blackouts. However, as was seen in the case of Nakano City, even though the local authorities had implemented a system for the registration of people who desire assistance in the event of an extraordinary disaster in order to confirm the safety of these individuals, this system did not function after the March 11th earthquake. And the response of governments, including the national government, to the planned blackouts was inadequate.

Why was the situation on the ground not better understood by the local authorities? I think the reason lies in the insufficient cooperation within administrative organizations and between governments and medical institutions and welfare facilities. Within the Nakano City administration, responsibility for people with disabilities who require medical care is spread among multiple sections. To begin with, responsibility is divided among the child and family support center, which is in charge of children, the health and welfare center, which supports people with intractable diseases, and the disability welfare section, which provides assistance to people with disabilities. Regarding alerts and encouraging preparations for the planned blackouts following the recent disaster, each of these three sections worked with the people under its jurisdiction separately. Since there was no one section covering all of these cases together, in order to find out what sorts of results were obtained it was necessary to contact each of the three sections separately. It is a problem that there is no section covering all responses regarding people with disabilities who require medical care and that information is not shared between the three sections involved.

In addition, government services are fundamentally provided on the basis of application, and as a result while the government has information on those who have applied for welfare service or disability identification booklet, it does not have sufficient knowledge of those who have not applied for these documents. People with disabilities who require medical care are always receiving treatment and are thus always connected to a medical institution. It cannot be said, however, that there is sufficient cooperation

between the government and medical institutions. The current state of affairs seems to be one in which the government takes the view that responding to the needs of those who require medical care is the responsibility of medical institutions, while medical institutions take the view that only specialist institutions should treat these individuals. In order to support people with disabilities who require medical care, cooperation between medical institutions in charge of providing medical treatment and governments that provide welfare and public health services is needed.

This interview survey of people with disabilities who require medical care living in the capital area following the 2011 Tohoku earthquake has demonstrated that a clear understanding of the circumstances of people with disabilities who require medical care is needed in order to create policies addressing the confirmation of safety and planned blackouts. To this end, the construction of a collaborative system involving both the medical and welfare fields is essential.

(Revision of a paper originally published in “Core Ethics” 8)

## Notes

[1] TEPCO used the term “rolling blackouts (rinbanteiden),” but as “planned blackouts (keikakuteiden)” was reported in the media and widely adopted this term will be used in this paper.

[2] “Concerning the response to the needs of people with disabilities who require care affected by the March 11th earthquake off the pacific coast of the Tohoku area” notification issued by the Ministry of Health, Labour and Welfare on March 11th, 2011

[3] When a woman with a severe disability in City T asked for public funds to cover new costs related to her care as an evacuee her request was rejected by the city. After the earthquake the national government issued a notice calling for a flexible response regarding people with disabilities, and other local authorities accepted similar requests for support. The woman has asked the prefecture to investigate.

[4] Amyotrophic Lateral Sclerosis (ALS) is an intractable disease (“nanbyo”) in which the muscles progressively weaken until no strength remains. It becomes difficult for the body to breathe on its own, and patients then undergo a tracheotomy and live attached to a mechanical ventilator.

[5] The daycare facility was equipped with manual suction machines, electrically-powered inhalers, and manual respiration assistance devices. The care centers were equipped with manual suction machines (pedal type), electrically-powered

suction machines (rechargeable type), inhalers (rechargeable type), artificial resuscitator (manual type).

[6] Results such as that 36.9% did not have external batteries, 11.1% had generators, and 12.1% had pedal type suction machines showed that the securing of power sources for use during a blackout was inadequate.

[7] A facility in Nagoya City supporting the lives of people with severe disabilities in the area. It operates “Wadachi Computer House,” a place where people with severe disabilities work, and “Samaria House,” a community residence. It has initiated a project to provide support to people who require assistance in the event of a disaster, and engages in providing assistance to people with disabilities when a disaster occurs.

#### Works Cited/Further Reading

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