

KEY POINTS FOR SUPPORTING CHILDREN/PERSONS WITH DEVELOPMENTAL DISORDERS IN DISASTERS

**A Guide for Everyone on How to Respond to Persons with
Developmental Disorders**

Editor
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**NATIONAL REHABILITATION CENTER
FOR PERSONS WITH DISABILITIES
JAPAN**

(WHO COLLABORATING CENTRE)

October, 2016

The National Rehabilitation Center for Persons with Disabilities was designated as the WHO Collaborating Centre for Disability Prevention and Rehabilitation in 1995.

The terms of reference are.

- 1 To collaborate with WHO in the development of knowledge and resources for increasing access to quality health, rehabilitation services and sports for persons with disabilities in the Western Pacific Region.
- 2 To support and cooperate with WHO to conduct capacity development activities and share good practice and experiences regarding disability and rehabilitation across the region.
- 3 To work with WHO to increase the awareness and understanding of the needs and rights of persons with disabilities.

National Rehabilitation Center for Persons with Disabilities
WHO Collaborating Centre for Disability Prevention and Rehabilitation

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Key Points for Supporting Children/Persons with Developmental Disorders in Disasters

October 3, 2016

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PREFACE

When a disaster strikes, conducting evacuations and confirming people's safety are very important. Afterward, it is often unavoidable that many must live at evacuation centers and other shelters.

Persons with developmental disorders have tremendous difficulty coping with such new environments. Being among masses of strangers at an evacuation center, where the usual foods or games are absent, and where one must stay quiet, can place a huge physical and psychological burden on people with developmental disorders and their families.

Persons with developmental disorders and their families who were affected by the Great East Japan Earthquake of March 11, 2011 were caught in situations that were difficult in many ways. The Information & Support Center for Persons with Developmental Disorders of the National Rehabilitation Center for Persons with Disabilities collaborated with interested parties from the disaster-affected areas to conduct a study on those people with developmental disorders who were affected by the disaster (and their families), and they compiled the booklet, *Key Points for Supporting Children/Persons with Developmental Disorders in Disasters: A Guide for Everyone on How to Respond to Persons with Developmental Disorders*. The booklet introduces the preparations ordinarily expected for persons with developmental disorders and their families, and it outlines the understanding and cooperation that should be given as part of disaster management or when supporting disaster-affected regions. Now, in various places around the world, natural disasters such as earthquakes and floods are occurring. Based on this booklet, the National Rehabilitation Center for Persons with Disabilities has decided to publish the WHO manual, *Key Points for Supporting Children/Persons with Developmental Disorders in Disasters*.

This manual is expected to be used by those involved in supporting individuals with developmental disorders in disaster-affected areas, or by the many people preparing or creating plans for disaster management, so that it may lead to the provision of understanding and support for developmental disorders and future disaster management that reflects this.

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Pullout : Support for Children/Persons with Developmental Disorders

Introduction

In the Great East Japan Earthquake that occurred on March 11, 2011, persons with developmental disorders such as autism spectrum disorder found themselves in an even more difficult situation because of their difficulty in adapting to changes in their living environment. Even now, many of these persons are still living in temporary housing or other refugee living environments.

Subsequent to the Great East Japan Earthquake, other large earthquakes have occurred around the world, such as the Indian Ocean Earthquake that occurred off the northwest coast of Sumatra, Indonesia on April 11, 2012 and the Lushan Earthquake in Sichuan, China on April 20, 2013, and we can reasonably expect a large earthquake accompanied by a tsunami to occur again. During ordinary times, it is important to compile key points concerning responses to these natural disasters and to be mentally prepared. Likewise, it is also crucial to provide appropriate information pertaining to support and consideration for persons with disabilities, who are especially vulnerable to the effects of disasters.

Recently, the National Rehabilitation Center for Persons with Disabilities (“the Center”) has published the rehabilitation manual, *Key Points for Supporting Children/Persons with Developmental Disorders in Disasters*. This rehabilitation manual has been created to inform people about the special needs of children/persons with learning disabilities. One of these special needs is gaining the understanding and cooperation from persons when required. The manual is based on a booklet created by the Information and Support Center for Persons with Developmental disorders, which has been established at the Center, and the key points are based on real-life experiences from the Great East Japan Earthquake and other prior earthquake-related disasters.

We hope that this manual will prove useful for many people involved in supporting those with developmental disorders and their families and that it will be used for practical situations in a wide range of locales.

Note:

In Japan, the Support Law for People with Developmental Disorders was established at Diet session in 2004 and enforced in April 2005. In this law, Developmental Disorders were defined as brain dysfunction that is generally expressed during earlier age such as Pervasive developmental disorders (autism, etc.), Learning disabilities, Attention deficit hyperactivity disorders, etc.

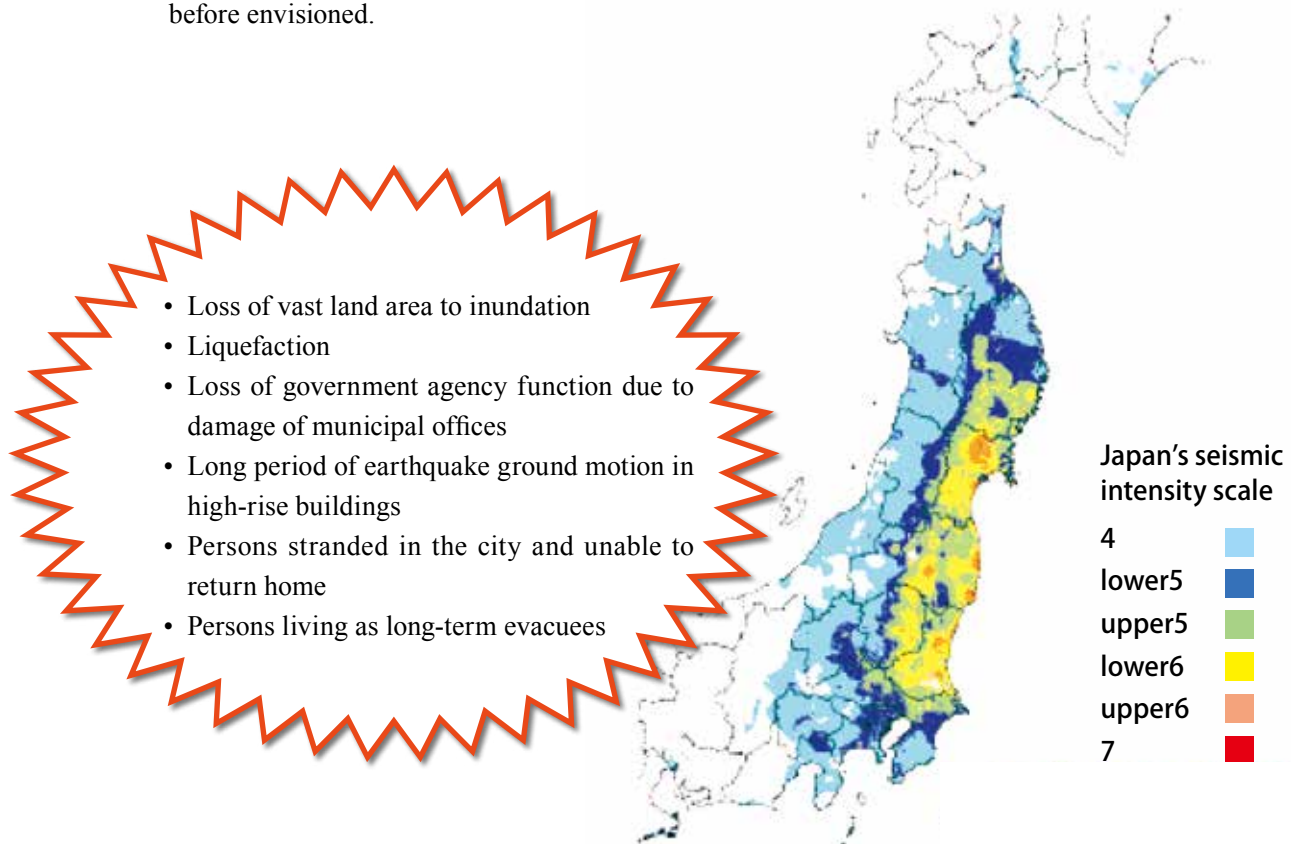
Chapter 1.

The Great East Japan Earthquake and Children/Persons with Developmental Disorders

On Friday, March 11, 2011, at 2:46 p.m., a gigantic earthquake of magnitude 9.0 occurred with an epicenter located off the coast of the Sanriku region (northeastern Honshu). In the northern region of Miyagi Prefecture, the quake measured 7 on Japan's seismic intensity scale, and the areas in which 6 or lower was measured included as many as eight prefectures centered on the Tohoku (north Honshu) region. The Pacific Ocean side of the coastline was struck by a massive tsunami, which inflicted terrible damage in various regions. Compounded by the subsequent nuclear power plant accident, the disaster caused serious and terrible devastation. Even now, many people have no choice but to live as evacuees.

Amid expectations that the disaster-affected people would have to endure “evacuation living” for a prolonged period, the government (Reconstruction Agency) formulated the *Comprehensive Measures for the Health and Living Support of the Disaster-Affected* (August 2014). These comprehensive measures address numerous issues faced by disaster-affected individuals on the ground and include enhancing the support structure, schemes to form communities based on where people live, reconstruction of the disaster-affected people's “spirit,” support for children, and the sharing of information infrastructures.

The Great East Japan Earthquake was an enormous disaster on a scale without precedent in Japan, and the numerous and immense hardships that followed led to the emergence of various issues never before envisioned.



Seismic intensity map (White Paper on Disaster Management 2011, Cabinet Office)

Major earthquakes in Japan (last 20 years)

- The Great Hanshin-Awaji Earthquake

This was a near-field earthquake that occurred at 5:46 a.m. on Tuesday, January 17, 1995.

Many of the disabled and the elderly who were living in the evacuation centers experienced deterioration of health and encountered hindrances to daily life. These experiences led to the institutionalization of “welfare evacuation centers.”

- Chuetsu Earthquake, Niigata Prefecture

This occurred at 5:56 p.m. on Saturday, October 23, 2004. The aftershocks continued and there were many reports of secondary damage, such as deep vein thrombosis due to sleeping in cars and disuse syndrome caused by living for extended periods as an evacuee.

Many lessons that we learned from these bitter experiences were applied to Japanese disaster management.

Large earthquakes around the world (since the Great East Japan Earthquake)

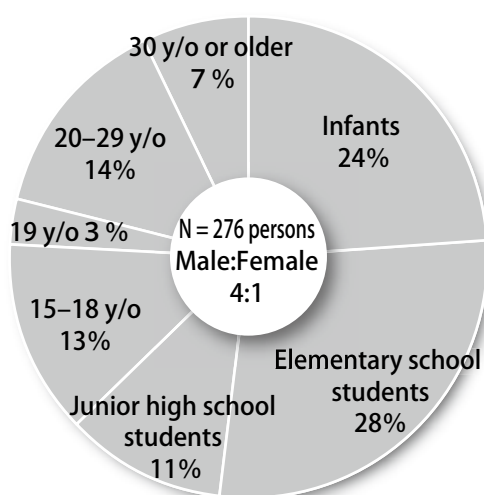
Date	Earthquake	Place	Magnitude
October 23, 2011	Van Earthquake	eastern Turkey	7.2
April 11, 2012	Indian Ocean Earthquake	northwest of Sumatra, Indonesia	8.7
April 20, 2013	Lushan Earthquake	Shichuan, China	7.0

Survey on use and support of disability welfare services based on the needs of children/persons with developmental disorders

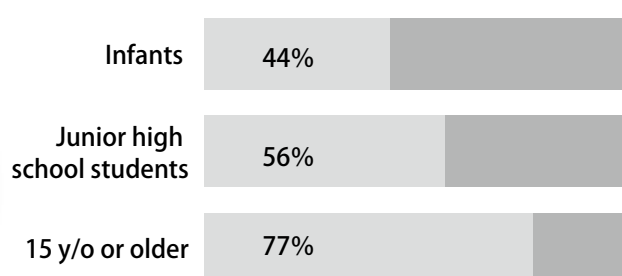
Purpose:	To gain a detailed understanding of the needs of children/persons with developmental disorders in the disaster-affected regions of the Great East Japan Earthquake and to provide disability welfare services based on this.
Survey regions:	Iwate Prefecture, Miyagi Prefecture (excluding Sendai City), and Fukushima Prefecture
Survey period:	February to March, 2012
Respondents:	Children/persons with learning disabilities (or their family responding by proxy)
Format:	Written questionnaire

The Information and Support Center for Persons with Developmental Disorders conducted a survey with the purpose of comprehending the circumstances and understanding the needs of children/persons with developmental disorders in disaster-afflicted regions. The results were posted on the website of the Information and Support Center for Persons with Developmental Disorders (<http://www.rehab.go.jp/ddis/> [in Japanese]).

Breakdown of the respondents



Disability passbook holders



Over 93% live with family

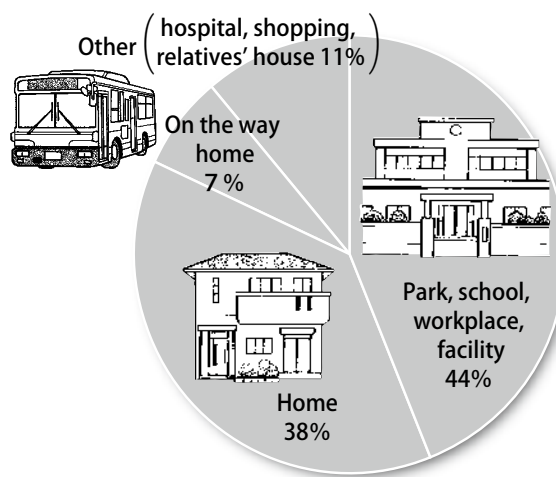
Chapter 2.

Understanding the Disaster's Impact through Answers to the Questionnaire

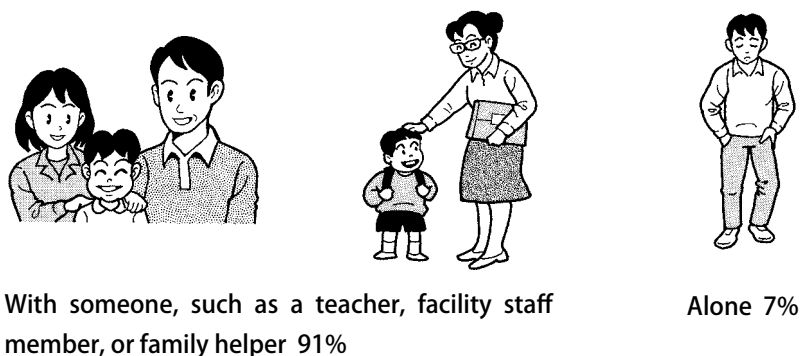
Chapter 2 compiles the information learned from the questionnaire concerning how children/ persons with developmental disorders and their families lived after the earthquake disaster, what kind of troubles were encountered, and what kind of action and support were effective.

1. Children/Persons with Developmental Disorders and their Families on March 11

Where were you when the earthquake occurred?



Who were you with?



How students responded at schools when the earthquake struck...

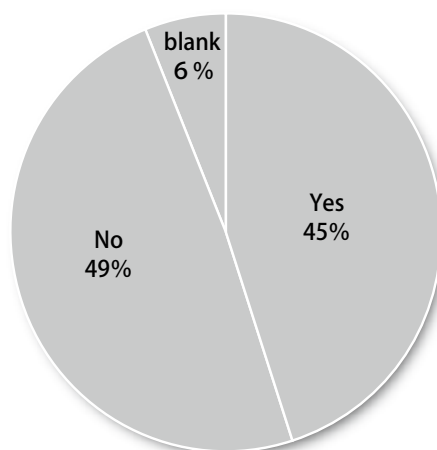
Most students acted as was instructed, such as getting under their desks, owing to regular evacuation drills. Those who panicked out of fear and anxiety accounted for 11.5% at regular classes in elementary schools and 14.3% at special support schools.

Safety confirmation at schools...

- Alternative methods to use in case the phones were not working had not been considered.
- In some cases, safety of the student was confirmed by direct visit or information from their neighbors
- Schools became evacuation centers and safety confirmation had to be carried out while attending to evacuees.

(Research survey into the responses of schools at the time the Great East Japan Earthquake, Ministry of Education, Culture, Sports, Science, and Technology, May of 2012)

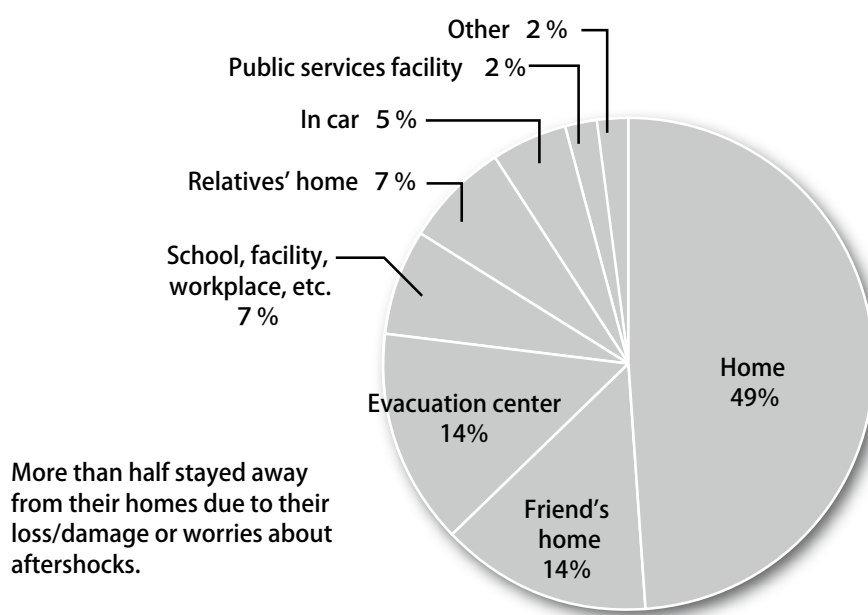
Were there safety confirmation inquiry from public institutions?



	No. of respondents
School, workplace	87
Welfare facility	22
Administrative agency	20
Hospital, Rehabilitation center, Center for persons with developmental disorders, Preschools or schools they have graduated from, Autism society	18

Note: Confirmed from multiple sources 16 persons

Where did you spend the night on March 11th?



A person requiring special help during a disaster

is someone who is unable to evacuate or cope with daily life on his own during a disaster.



Foreigners



Persons with disabilities or illnesses



Expectant mothers

About 90% of respondents replied that they did not know the existence of registry system for persons requiring special help . Only four persons answered that they were already registered.

Note:

The term of 'a person requiring special help during a disaster' was newly defined in Basic Act on Disaster Control Measures, 2013.

Measures for persons requiring special help during disasters

The Japanese government have created a registry of persons who require special help in accordance with the *Guideline for Evacuation Support for Persons Requiring Special Help* (March 2006) and had been urging the municipalities to prepare measures and plans of evacuation support for persons who required special help.

However, when the Great East Japan Earthquake occurred, the actual situation was as follows.

- The communication of information was inadequate.
- Registry for persons requiring special help during a disaster was not effectively utilized.
- The evacuation centers and emergency temporary housing were not made barrier free.
- There were many evacuation centers that were unable to meet the needs of persons who had difficulty with communal living.

(White Paper on Disaster Management 2012, Cabinet Office)



The aforementioned guideline was revised, and the government announced that it had newly created the *Guideline for Initiatives for Assisted Evacuation to Support Persons Requiring Assisted Evacuation* in August of 2013.

Municipalities should

- create an overall plan and establish a network for cooperation with relevant organizations
- know beforehand which person in the region requires attention during a disaster.
- make a registry of persons who need assisted evacuation and, upon their consent, give the lists to the support providers.
- secure means of communication by utilizing multiple modes and devices.

Joint Self-Help and Cooperation

What the regional community can do

- Prepare a disaster management plan that includes consideration for persons requiring attention and assisted evacuation.
- Conduct disaster management drills to test whether the plan actually functions.
- Continue efforts to establish network for cooperation and facilities in the regional community.

For Safety Confirmation...

- A registry for persons requiring assisted evacuation would be useful.
- Cooperating with schools and providers of welfare services is effective.

2. Difficulties in Life Immediately after the Disaster

On the day of March 11, in bitterly cold weather that included flurries of snow, power and gas supplies were stopped in the disaster-affected areas. The absence of the lifelines of electricity, water, and gas as well as the lack of a means of communication had a huge impact on living conditions immediately after the disaster, and it brought about even more difficult situations for persons with developmental disorders.

Troubles immediately after the disaster

	No. of respondents
Trouble securing daily essential supplies	182
Lack or disruption of information	168
Lack/restriction of means for transportation	165
Deterioration of physical or mental state	132
Closure of schools, facilities, workplaces, etc	120
Restricted daytime activities	117
Worries about money	99
Lack of medical treatment/medication	84
Nuclear Plant accident related worries	82
Work related matters	82
Bureaucratic procedures	53
Lack or insufficient welfare services	51
Difficulty in finding a shelter	45

N = 276 (Multiple choice, multiple answers allowed)

When electricity was cut off ...

- “He wanted to watch a DVD so badly, he became absolutely uncontrollable in panic” (13 y/o).
- “She burned her hair and eyebrows on the candle flame. She was interested in flames, and it was a problem” (8 y/o).

When the water supply was cut off...

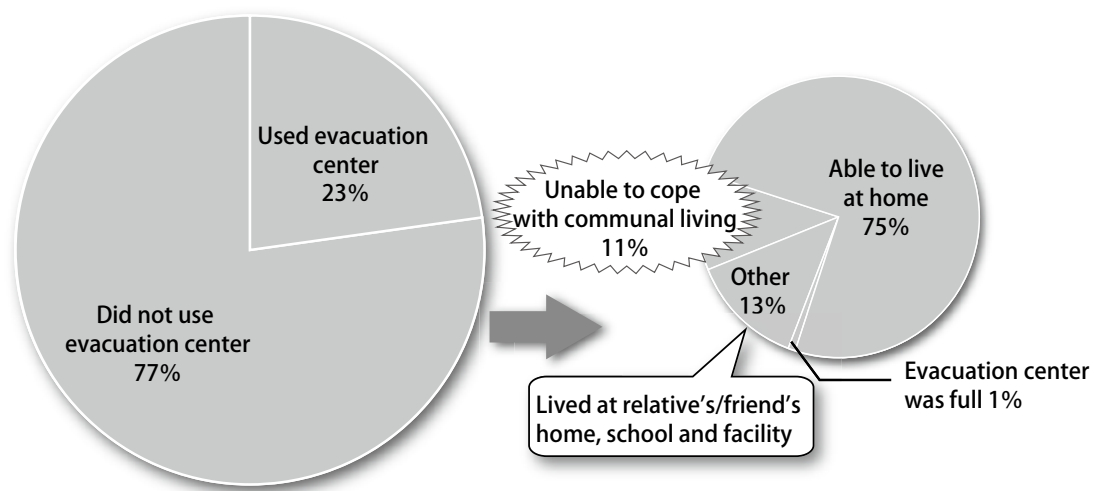
- “He could not use the toilet and started to wet his pants. Now, he is still incontinent.” (10 y/o).

Note:

The age in parentheses indicates the age of the individual with developmental disorders.

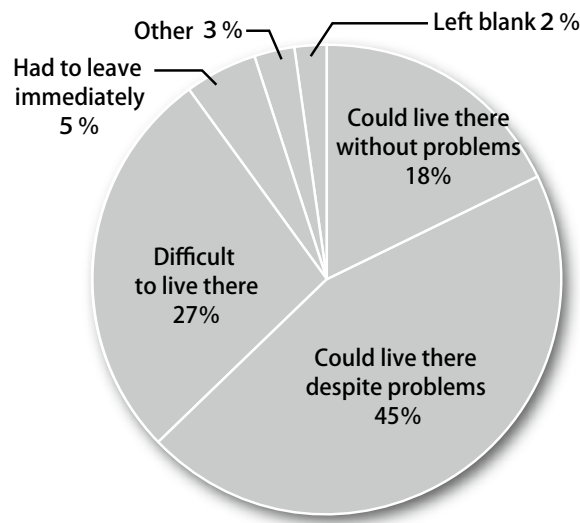
3. Was an Evacuation Center Available for them?

Were they able to use an evacuation center?



- “She could not control herself nor keep quiet. She would talk aloud to herself and do her jumping up and down. Whatever she did was a nuisance for others there.” (12 y/o).
- “He is very sensitive to noise. He hates places where there are many people, especially places like gymnasiums where all sort of echoing sounds get mixed up. He seemed to confusedly think that it was time for gymnasium because we were staying in a gymnasium.” (16 y/o).

How was the life at the evacuation center ?



- “As she would wake up in the middle of the night screaming, we stayed in the car for two weeks” (7 y/o).
- “Even after taking a tranquilizer, his panicking did not subside, and he just became more hyperactive” (10 y/o).
- “ At the time when things were really difficult, she couldn’t stop herself from repeatedly saying, ‘I’m hungry’ and ‘I want to go to the toilet,’ and it was so stressful to imagine what others would think of that” (44 y/o).

- The environment of the ordinary evacuation center, where many people were crowded together in a confined space, was a difficult place to stay for persons with developmental disorders.
- It was very stressful for the families, who constantly worried not to trouble people around them.

What is needed to be able to stay in the evacuation center?

Partitioned-off spaces or private rooms

- “When we received a fence and a wooden screen, which cut off the field of vision, I think he settled down considerably” (10 y/o).
- support persons • “It was a great help to be given use of a room only when sleeping.”

Someone with whom we could talk and discuss about our problems

- “As the municipal public health nurse was also there, we were lucky to have had an opportunity to seek advice” (56 y/o).

Techniques or devices that could be used indoors to keep them quiet.

- “As only news was being showed on the evacuation center TVs, I let her watch children’s programs on the mobile phone’s One Seg TV. We were able to recharge battery which really helped.” (9 y/o).

Welfare evacuation center

A welfare evacuation center is a location that has been designated by the municipal government for persons who have difficulty with the communal living of ordinary evacuation centers, such as bedridden elderly, those with a disability, expectant and nursing mothers, and so forth. The facilities must satisfy conditions, such as being made earthquake proof, barrier free, and having caregiving personnel, and the designated facilities are often homes for the elderly and custodial care facilities for persons with physical disabilities.

However, in this survey, only three people were reported to have used a welfare evacuation center. There were insufficient numbers of welfare evacuation centers, and there were inadequate personnel or materials (beds, wheelchairs, etc.) required to support. Moreover, only a few of the welfare evacuation centers had given consideration to persons with disabilities, expectant and nursing mothers, and newborns.



- When providing evacuation centers, consideration should be given to a diverse range of disaster- affected persons.
- Designation of welfare evacuation centers should be promoted and made widely known.
- Adequate personnel who can provide support should be secured.
- A system should be constructed that establishes cooperation among various parties, including residents of the region, volunteer organizations, and private sector organizations.

Accepting the above points, the government (Cabinet Office) compiled and announced the *Guidelines for Initiatives to Secure Favorable Living Environments in Evacuation Centers* in August of 2013. Through these guidelines, municipal governments were urged to make efforts to secure favorable living environments in evacuation centers during disasters. Therefore, municipal governments must respond by ensuring that their scope includes support for persons requiring attention and stay-at-home evacuees, such as elderly persons requiring nursing care, children/ persons with disabilities, expectant and nursing mothers, newborns, persons with chronic illnesses and allergies, foreign nationals, and others, while taking into account the unique characteristics and actual circumstances of the region.

4. Essential Supplies for Evacuation Living

What was difficult about supplies?

	No. of respondents
Could not eat the supplied/stored food because of extreme preferences in food	48
The family could not receive supplies or go for shopping because the person needed supervision all the time.	44
Wanting to change clothes with slight stain or moist even though there were no extra changes within supplied clothes	16
Person refused to wear supplied clothes due to hyperesthesia or strong preferences	6

N = 276 (multiple choice, multiple answers allowed)

Persons with developmental disorders who had unique difficulties



Food

- “No matter how hungry he was, he couldn’t eat the emergency food” (10 y/o).
- “She would refuse food or drink, even if it was only the wrapping package that was different” (11 y/o).
- “I used a glass for him to drink with, and by cutting the bread in half or in quarters, and showing him what was inside, he was able to comprehend what it was, and I got him to eat it” (11 y/o).
- “As we had just done our once-a-month bulk shopping for food and drinks on March 11, we were lucky to have had plenty of food” (14 y/o).



Clothes and diapers

- “As my child wanted her own clothes, I had to wash the clothes soiled by the tsunami so she could wear them” (12 y/o).
- “She was unable to have a bowel movement, and we were unable to wash soiled items, and I had no choice but to wash them in the river” (13 y/o).
- “We could receive only one or two diaper. They said ‘He’s no longer that age.’ We were soon in trouble.” (5 y/o)
- “The Youth Support Station* distributed clothing” (24 y/o).

* Facility that helps young people with occupational issues find employment.



Obtaining medicines

- “The stoppage of public transport and a shortage of gasoline were obstacles in getting to the doctor. There should be some framework for persons with disabilities” (25 y/o).
- “We received the regular prescription from a pharmacy nearby, but because it was different in form from that she usually took, she couldn’t take it” (10 y/o).
- “I realized how important it was to always carry a list of medication he is currently on” (11 y/o).
- “I made sure that I always had about half a month’s supply of her daily medication” (15 y/o).



The supply distribution methods

- “It is absolutely impossible to wait in line for supplies with a handicapped child with you.” (10 y/o).
- “As stay-at-home evacuees, the ongoing shortages put us into a difficult situation” (5 y/o).
- “The information for ration didn’t reach our houses, and we would often know about it afterwards” (15 y/o).
- “It was a great help that the community center delivered rationed food for us every day” (17 y/o).

What each individual should prepare

- Extra supplies of medicines and prescriptions, particularly those that must be taken regularly.
- Keep a stock of emergency foods and *furikake* (rice seasoning) that the person can eat.
- Items to pass the time during life in evacuation (drawing utensils, books, portable music players, games, batteries, etc.).
- A support book, a “Help-me Card” .
- Keep these items ready at multiple locations in the house.

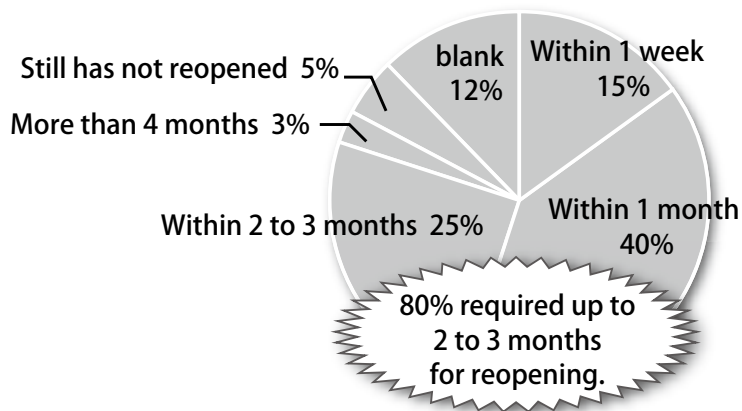
What the evacuation centers should prepare

- Some variety of stored foods to allow alternative choices.
- Large-sized ones included in the disposable diapers stock.
- Means/systems to give support to people living at home.

The August 2013 *Guidelines for Initiatives to Secure Favorable Living Environments in Evacuation Centers* also stated that the provisions at the evacuation centers should include considerations for persons requiring attention, and there should be strengthened systems of safeguard and ways to provide support and supplies for stay-at-home evacuees.

5. Returning to Ordinary Daily Life

When did the school, facility, or workplace reopen?



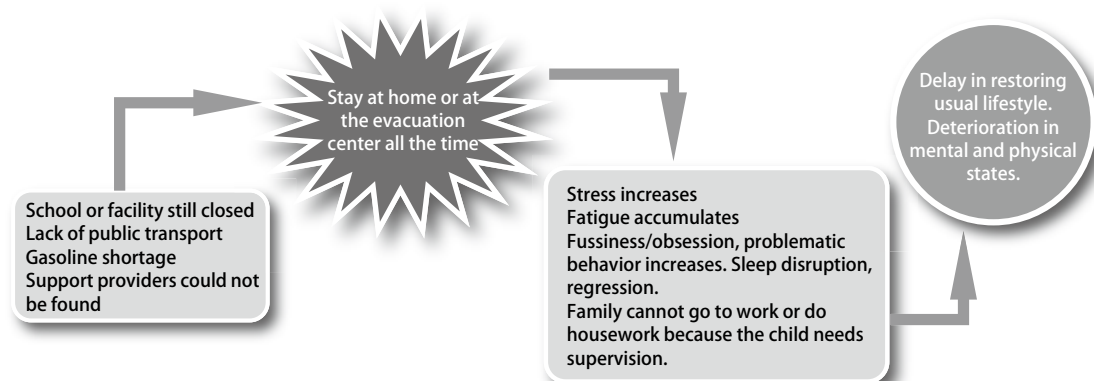
- “Even if it were just for the mornings, I wanted the day-care center to look after him” (6 y/o).
- “The children couldn’t understand the hazards of radioactivity, so though we explained, it was difficult for them to understand why they couldn’t play outside. I felt sorry for them.” (6 y/o).
- “Until school restarted, we parents couldn’t go to work because our child couldn’t stay by herself.” (16 y/o).

Were there any troubles with daytime activities or how to spend the day?

	No. of respondents
Unable to calm down because of lack of place to play and move around	77
It took a long time for schools or facilities took a to reopen	63
Unable to calm down because of a lack of play items for indoors	55
Could not go to school because of lack of public transportation and gasoline shortage	36
Could not stand separation from parents	35

N = 276 (Multiple choice, multiple answers allowed)

If daytime activities are restricted...



Furthermore, due to concerns about radioactivity, more activities were done indoors, which further added to the stress.

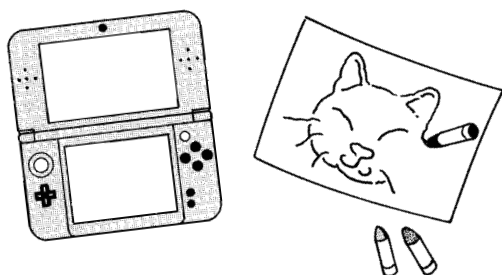
Business Continuity Plan (BCP)

There are calls for schools and welfare operators to open even for short periods whenever possible, though they may be affected by the disaster. It is important to establish a BCP during ordinary times.

- “It was a great help that the daytime temporary support restarted on April 1st” (10 y/o).
- “The hospital’s rehabilitation center reopened earlier than school, so we used it” (11 y/o).

Techniques and support useful when daytime activities are restricted

Appropriate indoor activities



Places for activities

- “We needed a place where children could play. We wanted a spacious area where our child could move around even for a short while” (5 y/o).

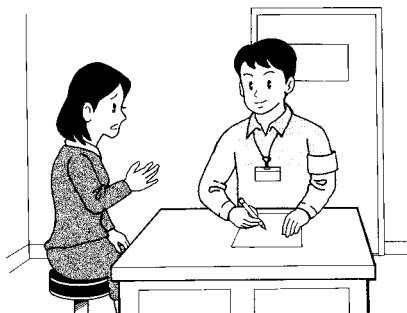
Someone to supervise or play with children

- “It really helped that volunteers and members of the police and self-defense force played with the children on their breaks” (8 y/o).



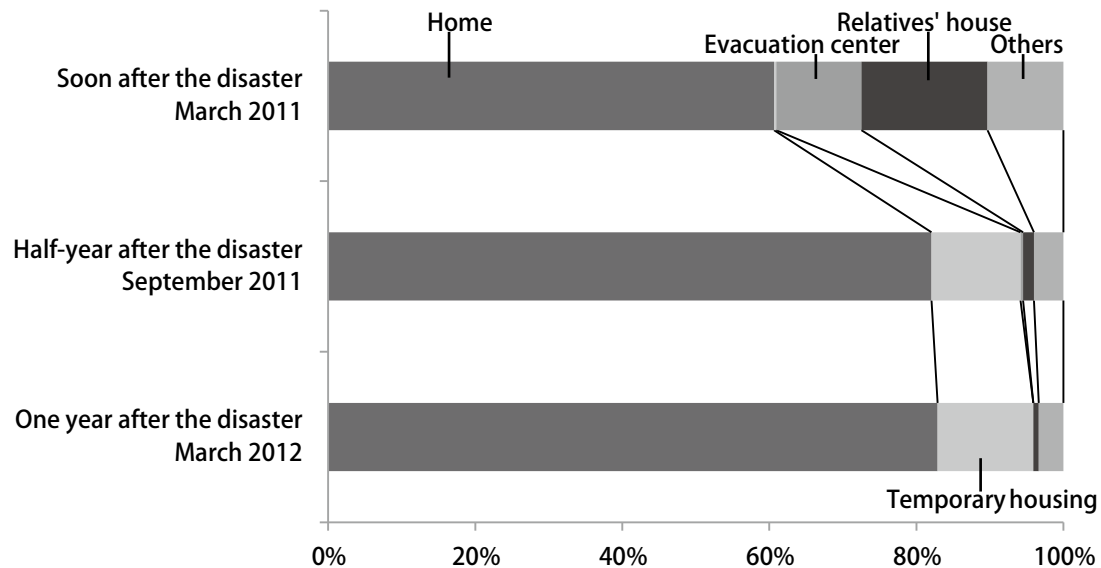
Someone the family can talk with about their problems

- “A community support advisor listened to all of my worries” (5 y/o).
- “We were comforted by the words from persons like the public health nurse.” (18 y/o).



6. One Year after the Earthquake

Where were you living? during one year from the earthquake ?



Immediately after the disaster, 40% of people lived outside their homes at evacuation centers, a relatives' house, etc. After half a year passed, more than 80% of people were living at home, and about 12% of people were living in temporary housing. This situation had not changed after a year.

One person said, "Our home was completely destroyed, but because of the hyperactivity and shouting, we decided not to apply for temporary housing" (5 y/o).

Troubles and difficulties at present

	No. of respondents
Damage from the nuclear accident	63
Economic worries	57
Deterioration in mental and physical health	48
Restrictions on daytime activities	24
Work-related issues	23

N = 276 persons (Multiple choice, multiple answers allowed)

We can see a large portion of anxiety concerns the nuclear accident. There are also some people who are avoiding outdoor activities. Economic troubles are continuing, and accumulated fatigue over a long period has caused deterioration in mental and physical health.

7. The Affected Areas Two Years Later

We spoke with staffs from the Miyagi Prefecture Center for Supporting Persons with Developmental disorders, “Ekubo,” and the Miyagi Prefecture Department for Disability Welfare in January of 2013, two years after the Great East Japan Earthquake.

Q. Please tell us about the situation immediately after the earthquake.

A. “The evacuation center was full of people, and there was no privacy. There was no more room, even for ordinary people.” “People evacuated to relatives’ houses, and it was then that the relatives first understood the child’s disability. Some became extremely fatigued due to the straining of relationships.” “Many of the registered persons gave their land-line telephone number, but most could not be contacted that way; the mobile phone was essential for confirming safety.” “People from the local advisory center walked around visiting people to confirm their safety.”

Q. What post-disaster initiatives were successful?

A. “We conducted parent training. This incorporated training of local supporters. We held it at one center on the coast in 2011 and at four disability health welfare regions in 2012. After the training, the parents’ level of depression improved, and the supporters who participated in training felt confident to broaden activities and individually hold parent training in their local regions.”

Q. What was the state of the adults with developmental disorders?

A. “They were probably not very good at recognizing when they were experiencing difficulties and asking for help.”

“We learned later that, at one of the places we went, there was one person who had to evacuate alone and panicked. Some advice will probably emerge from this. There was a young man who confined himself to his room after the family business was abandoned due to the earthquake. Some people who had been living well in the community and among family now needed to create new places to be.”

Q. What are the crucial points when preparing for an earthquake disaster?

A. “Directly following the earthquake disaster, various needs could be found here and there. Once things settled, the theme that emerged was “enhancement of welfare services,” and the way that welfare services had originally been set up began to be questioned.”

“During the earthquake disaster, information was obtained from the staff of the advisory centers, the public health nurses, and the schools’ teachers. It is important in ordinary times to create relationships where there is facial recognition so that this can lead to strong friendships and helping each other out in times of emergency.”

Overcoming the experience of the earthquake disaster, one step at a time

Chapter 3.

Professional Viewpoints: Various Forms of Support during a Disaster

1. Mental Care and Treatment for Stress

1) Introduction

The trauma of losing a significant person, being exposed to danger, and changes in daily life and the environment can lead to disaster-caused stress. Although the symptoms may vary depending on the type of stress, these symptoms tend to be more pronounced and more protracted in children/persons with developmental disorders. This, moreover, is a source of stress for the family and other people living together with that person. If supporters can promote understanding among the surrounding people while gaining acceptance from the person and the family, the mental burden on the family can be lessened. Understanding the nature of developmental disability and interacting in the spirit of helping one another will lead to reduced stress for all the people taking shelter.

2) Symptoms that emerge due to stress

Initial stage. With the supply of food and housing unstable and the safety of family members unknown, this is a time of social instability. The principal symptoms at times when great stress is suffered are anxiety and depression. In children, changes that are often seen under stress include regressive phenomena (bed-wetting, clinging, dependence, and disobedience), sleep disorders (night terrors, bad dreams), restlessness, hyperesthesia, irritability, crankiness, fright (extreme aversion to being left alone), headaches, abdominal pains, and hyperventilation.

- ▼ In the case of persons with a developmental disability, in addition to the above, symptoms of developmental disorders that had disappeared may once again develop and become stronger.
 - ◆ Conditions of hyperactivity and impulsiveness aggravate, and restlessness and irritability become noticeable, which can cause trouble for people around them.
 - ◆ Symptoms of inattentiveness worsen, and they are apt to be absentminded and fail to obtain or tend to lose necessary information and supplies.
 - ◆ Fussiness becomes extreme; they become particular about what food and clothes they will accept, they take longer in the toilet and the bath, and they will not obey rules. From the point of view of those around them, they are being selfish.
 - ◆ Hypersensitivity is aggravated. They more frequently feel things are not going as expected. They easily panic and continue for long periods of time to talk to themselves and exhibit stereotypical behavior, annoying the people around them.

Medium-to-long term stage. With food and housing having been supplied, and the safety of family members known, this is a time of social stability. For children/persons with developmental disorders, the state of anxiety is prolonged, and there are many who still remain unable to perform their study or work or to carry out daily life routines. Generally, in cases when the following symptoms continue, there is a possibility that the person is suffering a mental condition such as post-traumatic stress disorder (PTSD) or depression.

- ▼ When the symptoms of PTSD—such as (1) reliving events (thinking or dreaming about frightening experiences and feeling as if they were real, i.e., flashbacks), (2) avoidance (evading frightening experiences, experiencing loss of memory, not being in touch with one's emotions, and so on), and (3) heightened level of wakefulness (sleep disorder, irritability, restlessness, emotional instability, attention difficulties, and so forth)—continue after an injury, it could possibly be PTSD, and it will be necessary to seek professional treatment. Some children or persons with developmental disorders may have a history of reliving unpleasant events, and it is possible that PTSD could be overlooked in such persons.
- ▼ When there is a continuation in depressive state, depressive feelings, decline in interest and will, sense of helplessness, anger and frustration, decreased concentration, changes in sleep and appetite, and other such symptoms, the person can be considered to have depression, and it is necessary to obtain a diagnosis and treatment at a specialized hospital.

3) Best way to respond

Initial stage. The most important thing to do initially in the stage immediately after a disaster has struck is to make the person feel safe and at ease. One of the important foundations for making the person feel at ease is the stability of the guardian or adults around them. Stabilizing the fundamental elements of daily life, including safety, food, clothing, and shelter, is something that should be given priority over even psychological support.

It is important to make allowances so that the person's guardian can be nearby (for example, exempting the guardian from having to line up for supplies). It is important to promote understanding and provide assistance for people around them, thus alleviating the mental and physical strain on the guardian. It also is reassuring for the guardians when there is a place where they can go to immediately for advice.

Making it possible for the person to continue with normal routines and activities that had been carried out before the disaster (restoration of the schedule or environment that existed before the disaster and favorite items, television shows, places, etc.) will help put the person at ease. Children, and children/persons with developmental disorders try to overcome their anxiety and hardship through experiences of depending on and relying on family and people who care about them.

Efforts should be made to give appropriate information about the physical and mental changes that can be predicted and expected, and instructions should be given clearly. Explaining everything that can be explained and making it possible for the person to have a clear future outlook will make them feel at ease and lead to stability in their daily life.

Medium-to-long term stage. An important first step is to bring stability to daily life and secure a safe environment. However, if symptoms continue or gradually get worse, the advice of a specialist should be sought. If the disaster is understood to be the cause of manifested symptoms, these symptoms can be treated, even after several years. Bear in mind that the speed of mental recovery can vary significantly depending on the person and that it is necessary to take a long-term approach to their recovery.

4) Taboos and must-nots

- Avoid watching televised news and listening to radio broadcasts about the disaster.
- Discourage those nearby from using a loud voice to scold the person or from physically restraining the person, as it can have adverse effects.
- Avoid unnecessarily getting the person to talk about feelings or experiences (for a television interview, written article, etc.).
- Avoid probing into the root of the psychological problems until some fundamental stability is established in daily life.

Reference. The National Child Traumatic Stress Network and National Center for PTSD (both of the United States), *Psychological First Aid: Field Operations Guide* (Japanese version published in 2011 by Igaku Shoin Ltd.).

2. Dissemination of Information at the Time of the Disaster

The Great East Japan Earthquake was a large-scale disaster that occurred in an age when internet and social network services (SNS) had been developed. For example, we witnessed the dissemination of information about how one should actively respond in times of disaster from the websites of support centers, disability organizations, and individuals, such as specialists. Aside from the aforementioned dissemination of comparatively official or specialized information, there was also a flow of information in which SNS was used by individuals asking for support or thinking that they were posting useful information. Although it occurred rarely, there were examples of this kind of information being helpful.

The following highlights the various challenges and points out what to be prepared for in the future based on an examination of the information dissemination that occurred during the Great East Japan Earthquake disaster.

Information dissemination by websites

The use of websites belonging to centers, organizations, etc. for information dissemination about actively responding to the disaster can be effective. However, when this information has been posted on a website after the disaster has occurred, it can be a challenge to inform people about its existence. Therefore, to ensure utilization during disasters, it is important to write articles on websites during ordinary times about general measures that need to be taken in times of disaster, tell the users about the existence of the website, and urge them to bookmark the site.

Another important point when publishing information on a website is to publish the information in hypertext markup language (HTML) format rather than providing it as a portable document format (PDF) file. By using the HTML format, the information can be read easily not only from a PC but also from smartphones or other devices. While on one hand, the PDF format is useful because it is printer-friendly, when trying to read a PDF on a device with a small screen, it is difficult to display the entire document on the screen, making it viewer-unfriendly. As it may not be possible to use printers at the evacuation center, the dissemination of documentation in HTML is considered to be

the most appropriate. Another benefit of HTML format is that text-to-speech applications will be able to read the entire document, which is advantageous as a means of information dissemination for people with reading difficulties.

Information dissemination by social network services

From an analysis of information dissemination by Twitter, one type of SNS, it was found that SNS served a valuable role as a means of publicizing the existence of a website.*

The graph below shows the relationship between the number of visits via Twitter to the website of the National Rehabilitation Center for Persons with Disabilities and the number of tweets containing the center's website URL (link).

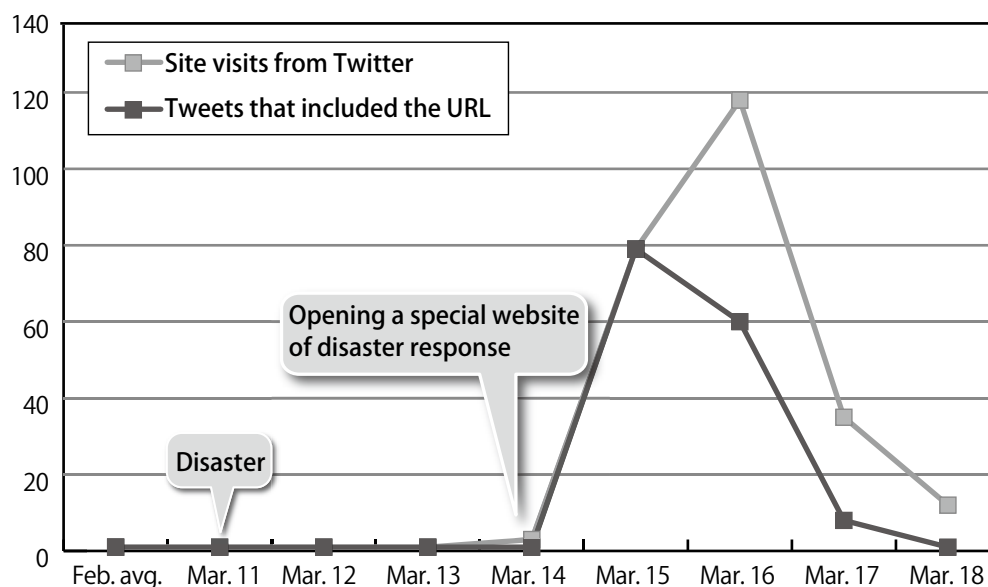
Twitter places restrictions on the character length of messages, and it is difficult to post lengthy information. It is therefore not possible to use Twitter to disseminate all of the necessary information.

On the other hand, as a person looking at a tweet can easily disseminate that tweet if that information were perceived to be useful, the act of disseminating tweets containing the webpage's URL, becomes a way of bringing people to the website. The graph shows that the number of tweets and the number of visits showed matching trends, and this can be interpreted as showing that Twitter is an effective method of bringing people to a website.

Furthermore, the same mechanism exists not just for Twitter, which was analyzed this time, but for other SNSs as well.

However, in the Great East Japan Earthquake, compared with the overall number of tweets, the associated information dissemination was only a small fraction of this, and a challenge to be addressed is identifying how to generate numerous forwarding and sharing actions regarding this type of information.

Trend of tweets containing the URL of the information center and visitors to the website



Summary (future recommendations)

To disseminate information effectively during a disaster, while it is important for centers and organizations to get into the practice of using websites and SNS in ordinary times, it is also important to examine the methods of disseminating information using the Internet when formulating the disaster management plan. Moreover, it is desirable that information dissemination and transmission training drills be incorporated into the disaster-management training drills.

* At a Great East Japan Earthquake Big-Data Workshop, tweeted data from the SNS Twitter was received from Twitter Japan, and this data was used to examine the information dissemination related to developmental disorders. An overview of this was reported at a presentation (October 28, 2012). The videos and slides can be viewed at the following URL (in Japanese):

“Project related to information provision to disaster-affected persons with special support needs during a large-scale disaster,”

<https://sites.google.com/site/prj311/event/presentation-session/presentation4#TOC--1>
(February 20, 2013).

3. Incorporating the Viewpoints of Children/Persons with Developmental Disorders into the Disaster Management Plan of Local Regions: The Case of Japan

1) Roles of the national government and municipal government bodies related to disaster management

In Japan, the Basic Act on Disaster Control Measures was first established after the Isewan Typhoon struck in 1959. The national government, the prefectural governments, and the municipal governments each created and implemented their own disaster management plans. To keep the plans from conflicting, role allocations were decided for each (Figure 1). In short, the national government created the disaster management basic plan and necessary laws. The prefectural governments established comprehensive coordination in cases where a disaster covered a wide area, and they carried out a portion of the processing of the municipal administration. The municipal governments were in charge of the work related to the local residents. It was the prefectural governments' role to transmit meteorological information and notices from the national government to the municipalities.

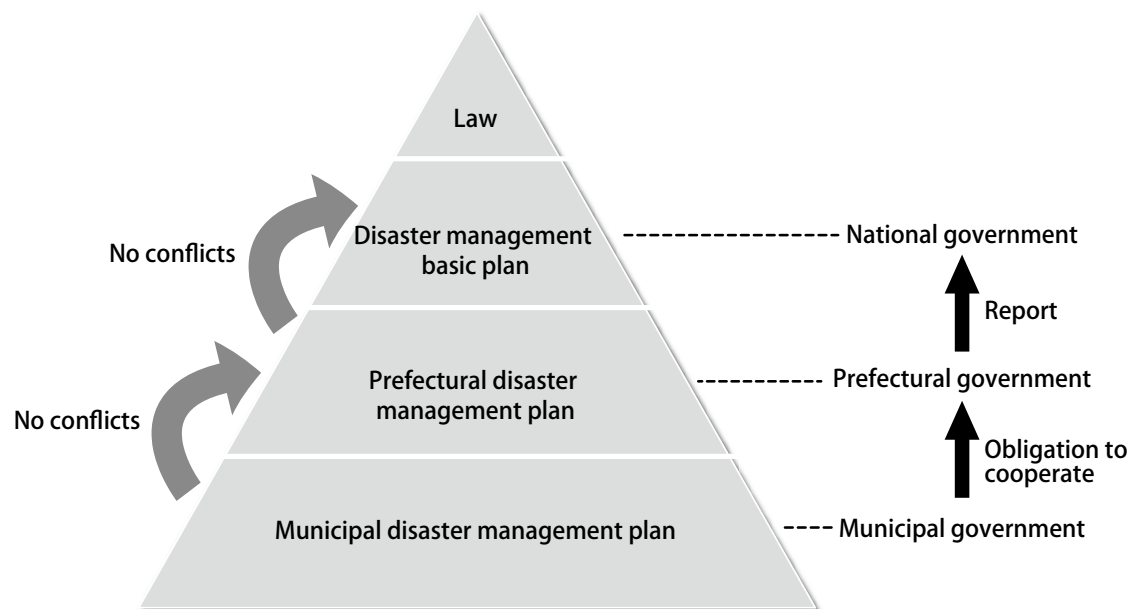


Figure 1. Role allocations between national, prefectural, and municipal governments.

The disaster-affected persons to receive support during disasters include those vulnerable to the effects of disaster, requiring support during a disaster, requiring attention during a disaster, and requiring evacuative support during a disaster.

The definition of terms such as “persons requiring support during a disaster” varies depending on the municipal government. At a national level, various examination reports (in Japanese) have been published. The Cabinet Office has published the *Guideline for Supporting Evacuation of Persons Requiring Support during Disasters*, *Examination Committee for Supporting Evacuation of Persons Requiring Support during Disasters (Report)*, *Case Studies of Evacuation of Persons Requiring Support during Disasters*, *Guideline for Initiatives for Assisted Evacuation to Support*

Persons Requiring Assisted Evacuation, and Guidelines for Initiatives to Secure Favorable Living Environments in Evacuation Centers. The Ministry of Health, Labor, and Welfare has published *Guideline for Establishment and Operation of Welfare Evacuation Centers*, the Ministry of Land, Infrastructure, Transport, and Tourism published the *Survey Research Report on the State of Barrier-Free Preparations and Information Provision for Evacuation Routes, etc. during Disasters and Emergencies*, and the Ministry of Education, Culture, Sports, Science, and Technology has published an examination report concerning a summary of *Provisions for School Facilities Following Damage of the Great East Japan Earthquake*. After the Great East Japan Earthquake, representatives of concerned-party organizations related to developmental disorders participated as members in committees organized by the national government, and matters requiring specific preparations—such as liaison meetings with persons requiring attention during disasters—held in ordinary times was also added.

At the prefectural level, the state of persons requiring support during disasters in the Disaster Management Plan was published, and more than 90% of prefectural governments are displaying the *Manual to Support Persons Requiring Support during a Disaster, Municipality Manual Creation Handbook*, and so forth on their websites. However, there were very few examples of enhancements being made to parts of the documents concerning developmental disorders. Moreover, there were some municipalities that created the *Evacuation Center Operation Manual, Welfare Evacuation Center Operation Manual*, and *Personal Information Handling Rules*. After the Great East Japan Earthquake, both the prefectural and the municipal governments proceeded to make revisions to documents, such as the *Manual for Persons Requiring Support during a Disaster*.

2) Cooperation between parent associations and the government

Beginning in 2003, the Saitama Autism Society submitted a request for disaster management measures for the developmentally disabled. This was followed up with a questionnaire administered to its members and ongoing lectures given to members of the local welfare commission and child-welfare commission to promote understanding of the developmentally disabled. As a result, a one-page entry on developmental disability was included in the *Manual to Support Persons Requiring Support during a Disaster* (2005), and a support book created by the Saitama Autism Society was introduced. Moreover, in 2011, a representative of the Saitama Autism Society participated in a working group to revise the prefectural disaster-management plan. This time, however, it was not limited to enhancing the entry on developmental disability in the *Manual to Support Persons Requiring Support during a Disaster*. As is often the case, the department in charge of disabilities is separate from the crisis management department and the disaster management that formulates the disaster management plan. It is important for parent associations to make requests and suggestions to the municipal and prefectural departments to include necessary contents in the plan. The Saitama Autism Society went on to create the *Emergency Response Manual & Handbook for People with Developmental disorders* (2014); in addition to donating 8,000 copies to be distributed to the fire and ambulance workers inside the prefecture, the society conducted training drills based on the distributed manual, in which the concerned parties and fire workers participated.

3) Connecting municipal disaster plan to individual evaluation plans

Municipalities are creating a registry of persons requiring support during a disaster (Figure 2). This

registry is passed on to the welfare commission members and neighborhood association chairpersons, and it is recommended that individual evacuation plans be created. It is also expected that overall evacuation plans and individual evacuation plans will be formulated locally (Figure 3). There are many different characteristics that children/persons with developmental disorders may have, and there are many cases where even the family does not know or cannot specify active response methods during a disaster. In such cases, it is effective to get the person, the family, supporters, and experts all involved in formulating a plan for specified hypothetical events and conducting a training drill. Doing so verifies that the children or persons with developmental or intellectual disabilities can faithfully execute the desired outcomes of the training drill [1].

All over Japan, individual evacuation plans have not yet to be formulated for each particular scenario, such as for earthquakes, fires, flooding, power outages, tsunamis, etc. when at school, at work, at home, while commuting, while travelling, etc. It is hoped that the creation of registries will lead to the promotion of activities that will increase what each child or person with a developmental disability can do in cases where family members or familiar providers of support are not in their immediate vicinity. It is necessary for the person to practice talking to strangers, asking them questions, and requesting assistance and that the person and neighbors are mindful of being prepared to create relationships with nearby individuals from whom support can be requested, promoting self-help and mutual assistance. The Autism Society of Japan has created the *Disaster Management and Support Handbook for People with Autism* (one edition for supporters and one for persons with autism and their families), and an electronic version of the handbook is available in Japanese and English at the following website: <http://www.rehab.go.jp/ri/fukushi/ykitamura/kitamurayayoi.html>.

					Year Month Day
					Consent to share information
To Mayor XXX,					
I give consent to the concept of the registry system for persons requiring assistance during a disaster, and wish to register with the system. Moreover, I give the city consent to pass on the below submission of personal information to autonomous disaster management organizations, health committee officers, social welfare associations, residential nursing facilities, the fire department, and the police department.					
Region name		Welfare commission officer		TEL. FAX	
Person requiring assistance during disaster (elderly person requiring nursing care, elderly person living alone, person with disabilities, other)					
Address			TEL. FAX	Information transmission methods including Internet (email, mobile phone email/ SMS etc.)	
Name	(male/female)		Date of birth		
Emergency contact (family, etc.)					
Name		Relationship ()	Address		TEL.
Name		Relationship ()	Address		TEL.
Family composition/status of co-inhabitants, etc. There are two of us: my wife and I. My son and daughter are both married and live outside the prefecture.			Structure of home	Wooden 2-story house, built 19XX (wood, steel framing, fire resistance). What is the house made of and when was it built.	
			Room where most time is spent		
			Location of bedroom		
Special notes: I require level 4 nursing care. I find it difficult to walk alone. I am receiving dialysis. I am also hearing impaired and it is necessary to use sign language.					
Emergency communication system (yes/no)				If it is not necessary to disclose information, such as the state of the physical handicap, presence of dementia, or detail of required support, then, taking privacy into consideration, it is not necessary to include this in the form.	
Evacuation supporters					
Name		Relationship ()	Address		
Name		Relationship ()	Address		

Figure 2. Example of an application form to be listed on the registry of persons requiring support during a disaster (from the Cabinet Office publication, Guidelines to Support Persons Requiring Support during a Disaster).

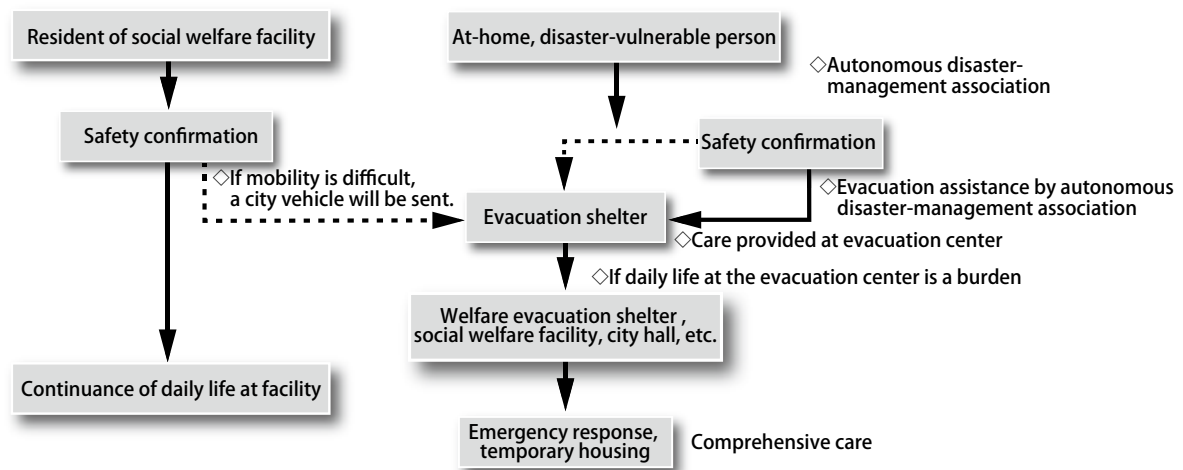


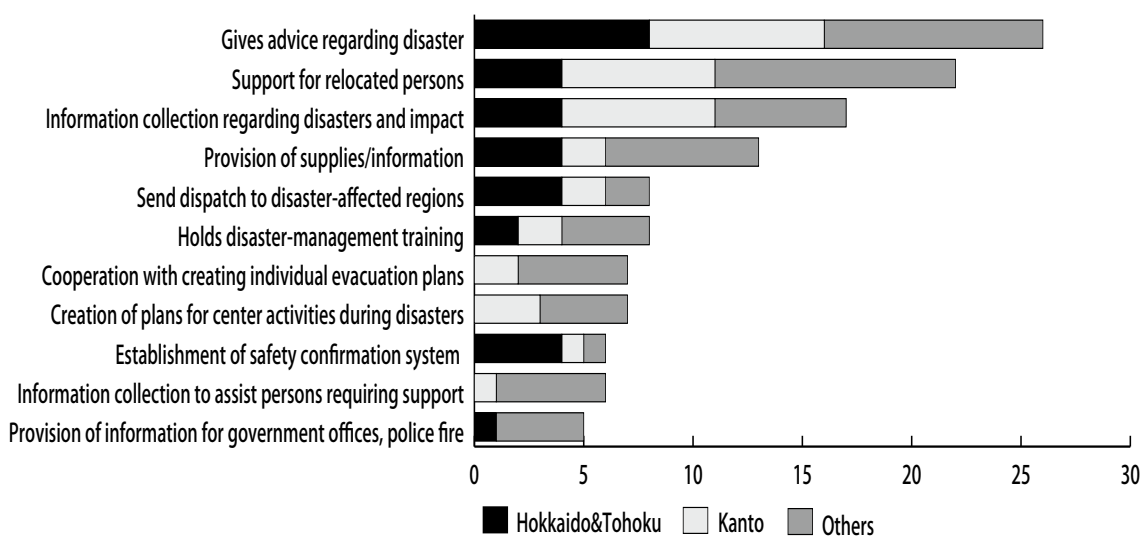
Figure 3. Example sequence of active response for persons requiring support during a disaster, as indicated by the local disaster management plan.

[1] Kitamura, Yayoi; Kubo, Yoshikazu; Kawamura, Hiroshi; *Planning and Effect of Fire Drills for Persons with Severe Autism at a Rehabilitation Facility*; National Rehabilitation Center for Persons with Disabilities Journal 26: 1–8, 2006. <http://www.rehab.go.jp/kiyou/japanese/26th/26-02.pdf> (English abstract).

4) Support Centers for Persons with Developmental Disabilities

Support Centers for Persons with Developmental Disabilities” have been established in prefectures and government-designated municipalities as specialist institutions with the purpose of comprehensively providing support to children/persons with developmental disorders. As of 2014, centers have been established in 86 locations. The following describes the kinds of activities that these support centers provide throughout Japan.

Activities conducted by Support Centers for Persons with Developmental Disabilities during one year following the earthquake.



In response to consultations with children/persons with developmental disorders, mostly in the Tohoku and Kanto regions but also including people who relocated across Japan, about 75% of centers have carried out some form of activity. There are also centers that have conducted research groups and provided information concerning disaster management measures targeting individuals and governments.

5) Information & Support Center for Persons with Developmental Disorders

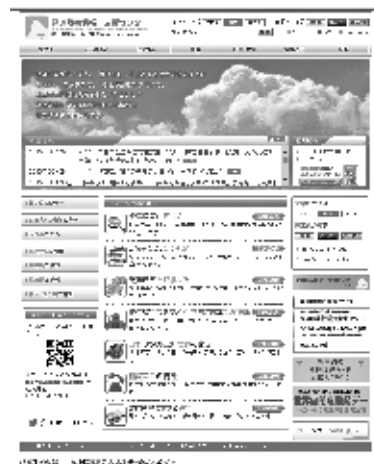
The Information & Support Center for Persons with Developmental Disorders was established in 2008 with the purpose of gathering and analyzing recent and reliable information about developmental disorders and promoting public awareness across Japan. Currently, it is positioned inside the National Rehabilitation Center for Persons with Disabilities, and its activities include information dissemination on its website (<http://www.rehab.go.jp/ddis/>), generating surveys and reports concerning developmental disorders, and providing information support for the support centers for persons with disabilities nationwide.

Initiatives of Information & Support Center for Persons with Developmental Disorders

1. Posted *To everyone supporting children/persons with developmental disorders in disaster-affected regions* on the website and distributed the leaflet (March-April 2011).
2. Implemented the *Survey on use and support of disability welfare services based on the needs of children/persons with developmental disorders* (February-March 2012).
3. Implemented a survey of support centers for persons with disabilities (November 2012),.
4. Published *Key Points for Supporting Children/Persons with Developmental Disorders in Disasters* (March 2013).

The website for the Information & Support Center for Persons with Developmental Disorders

The center provides reliable information
concerning developmental disorders in Japan.
<http://www.rehab.go.jp/ddis/>



Chapter 4.

To Everyone Supporting Children/Persons with Developmental Disorders in Disaster-affected Regions

In March 2011, immediately following the disaster, the Information & Support Center for Persons with Developmental disorders posted the article *“To everyone supporting children/persons with developmental disorders in disaster-affected regions,”* in three installments, for the benefit of active responders to persons with developmental disorders in disaster-affected regions (pp. 31–36)

In April, furthermore, we made a leaflet which is a digest version of three articles and distributed to the evacuation centers. This leaflet was posted in a center and you can also see it at the end of the book.

Part 1 March 15

Things you can do immediately

The following describes what the families, those in charge of the evacuation center should know.



At the evacuation center

The following is a compilation of requests from children with developmental disorders and their families. Persons with developmental disorders may not appear to have any disability at first glance. However, it will be necessary that they receive understanding and support from everyone.

■ When actively responding to persons with developmental disorders, certain techniques will be required. For example, when a person who understands the person's condition, such as a family member, is accessible, always check for any relevant information on how to engage.

Examples	<ul style="list-style-type: none">• “Are there any items they need (medicine, food, stationery, toys)?”• “Are there any matters to keep in mind (places where person relaxes, ways to verbally engage, etc.)?”
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■ Persons with developmental disorders often are worse than expected at responding to changes in their daily lives. As a result, they can become anxious and act strangely. Sometimes, they exhibit strong opposition when asked to do something. Therefore, provide the person with instructions that accurately describe what to do and with items that can be used to pass the time, and give clear instructions regarding changes in schedules and places.

Examples	<ul style="list-style-type: none"> • “Please sit on that seat” (Do not say, “Don’t go there!”). • Provide pencils and paper, puzzles, picture books, games, etc. (Do not make them wait without anything to do).
Examples	<ul style="list-style-type: none"> • “There isn’t XXX (planned item). We will do YYY.” (Do not pull their hand without any explanation). • “XXX is in YYY(location).” (Do not say, “It’s not here,” without further explanation).

■ A person with developmental disorders often can have either hyperesthesia or anesthesia, which means the person may respond to stimuli in unexpected ways. Sometimes they may not understand instructions that deal with matters of life and death, they may complain that there are too many people and are not able to be inside the evacuation center, and they may actually need medical treatment but still have a facial expression indicating that everything is fine.

Therefore, it is important that certain techniques be employed to provide explanations, give consideration to where they stay, and check their state of health.

Examples	<ul style="list-style-type: none"> • Explain using shapes that are visible to the eyes, such as letters and drawings, or actual objects. Use simple words and speak in a calm tone of voice. • Use the corner of a room, a separate room, a tent, etc. to ensure the person has a private space. • Do not rely on merely asking the person whether they have any injuries. Look over their body properly to check.
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At home

Daily life during a disaster is significantly different from daily life during ordinary times. It is necessary for responses to be based on daily life after the immediate response to the disaster has settled down.

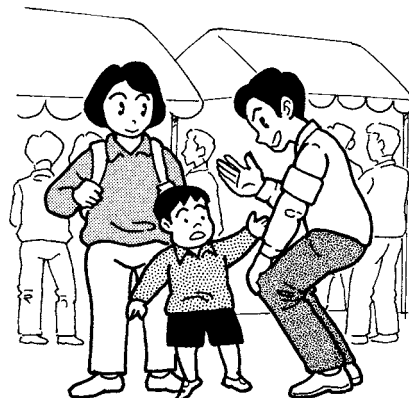
■ The situation in which you find yourself often includes unexpected situations, such as school or work closure, loss of power, and changes to television programming. When such disruptions occur, efforts need to be made to maintain stable daily-life rhythms. Therefore, techniques and strategies are needed, such as proposing new daily chores during that time or preparing in advance items that can be used to pass the time.

■ It is necessary to remain abreast of the status of damage through televised news and the like. However, especially if the person is a child, hearing about something happening to someone else can feel as if it were happening to oneself, and the impact could be a more frightening experience than expected. This has also been shown in surveys overseas. It is important to arrange for the child to spend the normal TV-watching time doing something else.

(March 15, 2011)

Utilizing knowledgeable people

Daily life in a disaster-affected region for persons with developmental disorders and their families can be hindered by various difficulties. In such cases, if there is someone who understands a little about how to respond to a person with developmental disorders, it can be a great help for everyone.



At the evacuation center

It is essential that there be a person present who is knowledgeable about developmental disorders and who can provide advice and judgment as to “how to communicate information,” “what kind of response is most suitable,” and “how to explain to other people who are not familiar with developmental disorders.” It is best to check the evacuation center regarding whether such a person is available.

- Cases when a person goes to a dangerous place, such as where the ground has become soft, or when a person touches a health professional’s medical equipment.

Examples	<ul style="list-style-type: none"> • Someone could attract the child’s attention to other types of play and chores that are interesting enough to hold the child’s attention. If there are any places the child must not go or items the child must not touch, someone could first mark an “X” on the place that the person must avoid or on the object that the person cannot touch. If there is someone who can actually propose such techniques, this might help avoid a troublesome incident.
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- When there is a child who cannot wait to receive water, food, and blankets.

Examples	<ul style="list-style-type: none"> • It really helps the family when there is a person who can be with the child in place of the family, and, together with the family, explain the characteristics of developmental disorders to surrounding people.
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At home

After the disaster, schools and facilities are closed, and there are cases where the children/persons with developmental disorders cannot go outside and must stay at home. In such cases, it becomes difficult for the families to cope by themselves; in order to provide a response to the child, some support will be necessary, or it may be necessary that someone visit the house to check on the

situation. In principle, a person from the respective local government agency would carry out this role. However, it sometimes can be useful if a person who has knowledge of supporting people with developmental disorders comes along as well.

- In cases where the aftershocks have continued, the family appears to be in a state of anxiety, and the child's fussy and demanding behavior and lack of proper sleep are prolonged, the family is troubled because it is unable to do the necessary chores of getting supplies, going shopping, and completing paperwork at the city hall or bank.

Examples	<ul style="list-style-type: none"> • It can alleviate the burden on the family when a person stays with the child/individual with developmental disorders in place of the family and when information is provided on the availability of mental health counseling, etc.
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- There are also cases of persons who become increasingly dependent on the family and of tasks for which the person was self-reliant before the earthquake but which can no longer be carried out by the person alone.

Examples	<ul style="list-style-type: none"> • The family can be put at ease by listening to the advice of counseling on individual issues, such as whether to encourage the person to do a task by themselves or whether it is okay to let them be more dependent because of the extraordinary circumstances.
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Items requiring understanding

The characteristics of persons with developmental disorders are different depending on the individual. When circumstances significantly differ from the methods of support they normally receive, the person in question can become very confused under the new circumstances. As much as possible, confirm the necessary items with the person in question, their families, and those who are familiar with said person's condition.

If there are any problematic points or issues that need further discussion with respect to the actual circumstances, this information should be communicated and voiced to the evacuation center or the person in charge at the time of the home visit. If support can be provided seamlessly, it will put the person with developmental disorders and the family at ease and lead to stability in daily life after the need for support is no longer required.

(March 18, 2011)

Noticing trouble

When life at evacuation centers or at home in different circumstances becomes prolonged, it gradually becomes physically and mentally fatiguing and stress accumulates. In order to recognize whether a person or family of person with developmental disorders is having trouble, certain knowledge or skills are needed. The following example shows what the signs are.



Check the state of health

In some cases of persons with developmental disorders, the person is not silently suffering a physical condition or injury; the person does not even notice the condition or injury. Left unattended, there are cases where a condition or injury becomes exacerbated, and it is therefore important to meticulously observe and ask questions.

Examples of visual signs	<ul style="list-style-type: none"> • Is there shortness of breath, frequent coughing, etc.? • Are there any burns, cuts, or bruises? • Is the person wearing clothes that are still wet?
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Examples of questions to ask	<ul style="list-style-type: none"> • “Are you feeling colder than usual?” • “Do you get dizzy when you walk?” • “Do you have any bumps on your head or cuts on your arms, legs, or feet?” • “Do you have a change of clothes?”
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Check for signs of stress

A person with developmental disorders may accumulate stress more easily than does a person without developmental disorders. Therefore, it is sometimes necessary to give priority to persons with developmental disorders when providing support.

Examples of visual signs	<ul style="list-style-type: none"> • Leaving lots of food uneaten on the plate out of pickiness about food. • Slow to react, even to the announcement that supplies had arrived, look unsure where to be, and appearing as if something is troubling them. • Covering the ears, closing the eyes, etc. Having a facial expression indicating discomfort with excessive stimuli.
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Examples of questions to ask	<ul style="list-style-type: none"> • “Was there something you couldn’t eat?” • “Do you know where to wait in line for the supplies?” • “Do you want to move to another place?”
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Check the condition of the family

There are cases in which the family does not get time away from the child or in which there is no one in the evacuation center with an understanding of persons with developmental disorders; these cause the family to experience greater stress. The people in charge of the person’s support for the longest time are the family, and it is effective to provide support for them swiftly.

Situations in which support is necessary	<ul style="list-style-type: none"> • When the family is bogged down taking care of a person who is exhibiting such behavior as hyperactivity and impulsiveness, making strange noises, panicking, or being extremely fussy. • When the family has been isolated because of a lack of understanding or cooperation from the surrounding people in the evacuation center.
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Specific questions to ask the family	<ul style="list-style-type: none"> • “During the daytime, which hours are the hardest for you?” • “What kinds of places are most difficult?”
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Check if there are anyone who can cooperate in dealing with the reaction of the child/person.

As the conditions that lead to deterioration of health or accumulation of stress are varied, it may be difficult to find the appropriate remedy. In cases where individual consideration is necessary, it is important to check whether there are people in the vicinity who know the person well and who can assist with such an reaction.

Situations in which it is necessary	<ul style="list-style-type: none"> • When at the toilet location or during meals, a person frequently comes to the center officers to ask questions. • When there is a person who is completely lost among the surrounding people, when a person with developmental disorders is repeatedly being scolded, or when someone is exhibiting different movements from the majority of the group.
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Specific questions to ask	<ul style="list-style-type: none"> • (To the person with developmental disorders) “When you have trouble, is there a person nearby who can give you advice? Whom do you normally ask for advice?” • (To others/surrounding people) “Is there anyone who knows what his/her normal state is? Is there anyone who can help provide care?”
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(March 28, 2011)

References: Useful Resources and Websites

The following provides useful resources and websites (in Japanese unless otherwise stated) for supporting disaster-affected persons.

Related to children/persons with developmental disorders

- *Support for children/persons with developmental disorders*: The Information & Support Center for Persons with Developmental Disorders
<http://www.rehab.go.jp/ddis/>
- *Handbook for teachers supporting children after an earthquake disaster: Focus on Responses for Children with Developmental disorders*. National Institute of Special Needs Education, April 2011.
<http://www.nise.go.jp/cms/6,3758,53.html>
- *Disaster Management and Support Handbook for Persons with Autism*, Autism Society of Japan, March 2012.
<http://www.autism.or.jp/bousai/index.htm>
There is a version for persons with autism and their families, and there is another for supporters.

Disaster management (prevention/mitigation)

- Cabinet Office. *Disaster management system* <http://www.bousai.go.jp/taisaku/index.html>
- *Disaster Management Plan*
Japanese version <http://www.bousai.go.jp/taisaku/keikaku/index.html>
English version http://www.bousai.go.jp/taisaku/keikaku/english/disaster_management_plan.html
- Assisted evacuation management
Guideline for Initiatives for Assisted Evacuation to Support Persons Requiring Assisted Evacuation, August 2013.
<http://www.bousai.go.jp/taisaku/hisaisyagyousei/youengosya/h25/hinansien.html>
- Management of daily-living environments in evacuation centers
Guidelines for Initiatives to Secure Favorable Living Environments in Evacuation Centers, August 2013.
<http://www.bousai.go.jp/taisaku/hinanjo/index.html>
- *Guideline for Establishment and Operation of Welfare Evacuation Centers*, Japanese Red Cross Society, June 2008.
<http://www.jrc.or.jp/saigai/shiryo/index.html>
- *Guidelines for Disaster Planning Response and Reconstruction from a Gender Equal Perspective*, May 2013.
<http://www.gender.go.jp/policy/saigai/shishin/index.html>
(The English pamphlet, Learning from Adversity, is also available)
- *Handbook for Creating a Disaster Management Manual for Schools (for Earthquake and Tsunami disasters)*, Ministry of Education, Culture, Sports, Science & Technology, March 2012.
http://www.mext.go.jp/a_menu/kenko/anzen/1323513.htm

The URLs provided above were valid as of December 2014.

Afterword

Three days after the occurrence of the Great East Japan Earthquake, the Ministry of Health, Labor, and Welfare sent a request to the Information & Support Center for Persons with Developmental disorders asking to manuscript and publish an article describing specific aids that can be provided to children/persons with developmental disorders. Immediately, *To everyone supporting Children/Persons with developmental disorders in disaster-affected regions* was written and published on its website the following day.

One year after the earthquake disaster, our center conducted a survey targeting a total of 276 persons consisting of persons with developmental disorders and their families in the Iwate, Miyagi, and Fukushima prefectures, where there were many disaster-affected persons.

In March 2013, based on the survey results, the center published the handbook, *Key Points for Supporting Children/Persons with Developmental Disorders in Disasters*. The target reader for this manual was not only those with developmental disorders or their families, but also their supporters and the general public.

This manual, an edited work based on the above pamphlet, includes subsequent changes made to the disaster-management system. This serves as a reference to mentally prepare a disaster and make substantial preparations for a disaster, hoping to contribute to a realization of a society where everyone may live happily.

Support for children/persons with developmental disorders

■ This leaflet is a digest version of “To everyone supporting children/persons with developmental disorders in disaster-affected regions (Part 1-3)”.

In a disaster, persons with developmental disorders and their families face various difficulties. They may not appear to have any trouble at first glance. It is necessary to have some knowledge to be able to deal with difficulties.



★ Check with someone close to the person, such as a family member, who understands the condition and knows how to deal with it.

In this case...

■ **Coping poorly with change**
might act strangely out of anxiety and exhibit strong opposition to approaches by others.



Respond like this...

- Give clear instructions in a calm voice.
Say “Please sit on that seat.”
Do not say, “Don’t go there!”
- Give clear details about changes in schedules and places.
Say “There isn’t XXX. We will do YYY.”
Do not pull their hand without any explanation.

■ **Unusual response to sensory stimuli**
Hyperesthesia: They are more sensitive to stimuli. As there are too many people in the evacuation center, they might not enter it.
Hypesthesia: May need medical treatment but fail to show any hint of this in their facial expression.



- Use the corner of a room, a separate room, or a tent to ensure the person has a private space.



- Check health state by looking over their body whether there are any injuries. Do not just ask if they are OK.

■ **Poor at verbal exchange and unable to communicate** problems.

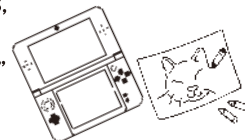


- Explain in a visible manner with letters and drawings or actual objects. Speak to the person individually, using simple and concrete words.

■ **Very anxious when things do not go as expected.**
Gets anxious about school or work being closed, power stoppages, or changes to television programs.



- Maintain daily life activities.
Propose new chores or provide activities to pass time. Provide writing implements and paper, puzzles, picture books, games. Ask them to do simple tasks such as handing out leaflets, or cleaning up a place.
Do not tell them to “just wait” nor “do nothing”



■ **Cannot recognize danger.**
Might go to dangerous places, or touch medical equipments.



- Invite to other interesting games or chores.
- Mark an easily identifiable “X” to avoid going to dangerous places or touching things.

To the Families...

★ Children tend to perceive events that have happened to others as if they had happened to themselves. Moreover, in children with developmental disorders, this could be a more frightful experience than one might expect. It is important to prevent children from watching television broadcast of the disaster, and have them spend time doing something else.

★ Check for health conditions and signs of physical or mental fatigue

Body

★ Sometimes persons with developmental disorders do not notice their own health condition or injury. Left unattended, their condition might get worse, so it is important to meticulously observe and ask questions.

Examples of visual signs:

- Is there shortness of breath, frequent coughing, burns, cuts, or bruises?
- Is the person wearing clothes that are still wet?

Examples of questions to ask:

- “Are you feeling colder than usual?”
- “Do you get dizzy when you walk?”
- “Do you have any bumps on your head or scratches on your arms, legs, or feet?”
- “Do you have a change of clothes?”



Stress

★ Things that are of no problem to most of the people might be quite unpleasant for a person with developmental disorders. They may accumulate stress more easily. There are times when prioritizing the support for the persons with developmental disorders are necessary.

Examples of signs:

- Leaving lots of food uneaten on the plate.
- Slow to react, even to the announcement of arrivals of supplies, looks unsure where to be, and appearing troubled.
- Covering their ears, closing their eyes or showing a facial expression that indicates excessive unpleasant stimuli for them.

Examples of questions to ask:

- “Was there something you couldn’t eat?”
- “Do you know where to wait in line for supplies?”
- “Do you wish you could move to another place?”

★ Check the condition of the family

Family

★ The family can become stressed when they can get no time away from the child or when there is no one who understands about developmental disorders in the evacuation center.

The people who are in charge of the person longest and who are most stressed are the family, and it is effective to provide support for them swiftly.

It can be a great help to the family if there is someone

- who would look after the child for the parents while the family do the chores, such as receiving supplies, going shopping, or completing paperwork at the municipal office, bank.
- who would explain to others about the characteristics of developmental disorders (under consent of the family), when the child is making a big fuss while waiting in line to receive supplies (water, food, and blankets).

★ Check for nearby people who can cooperate



★ Sometimes it is difficult to find an effective way to cope with. In cases where individual consideration is required, it is important to check whether there is someone around who know the person well and can work together to help him/her.

★ After experiencing a disaster, children might stop being able to do things they were able to do before the disaster, and they might tend to get agitated. With children with developmental disorders, generally increased dependency and some degree of regression are permissible. It is important to allow the children to restore their emotional stability slowly by talking to them in a calm voice and refraining from scolding them.