

Disaster Support for Children with Developmental Disabilities: Experiences During the Great East Japan Earthquake

Miyagi Disaster Mental Health Care Center
Community Support Department,
Director – Naru Fukuchi

The purpose of this section is to provide actual information on the Great East Japan Earthquake that occurred on March 11, 2011 and to reconsider support for children with developmental disabilities in the event of a disaster.

Approximately 400,000 people used evacuation shelters during the earthquake, including many people with special needs, such as the elderly and those with disabilities. Recent studies have shown that children with developmental disabilities are present in a certain proportion of almost any given population, and it is becoming widely recognized that they need understanding and support from those in their surroundings in their daily lives¹⁾. In the midst of social changes in disaster-affected areas, many children with developmental disabilities and their families lived in shame in evacuation shelters. Left in the midst of chaos, they responded in their own ways, which, unfortunately, made it difficult for others to work with them. It is imperative that we use this experience as a lesson to eliminate the problems present in current practices of disaster evacuation and support for children with developmental disabilities.

The content of this paper is not based on statistical analysis; rather, it is a report that summarizes the counseling that the author himself provided during patrols and in medical care settings, and draws from interviews with supporters and families involved with children with developmental disabilities. In consideration of the anonymity of those whose stories are told here, certain aspects of the case summaries unrelated to the main points of this section have been changed.

1. Responses Observed in All Children

(1) Regression

First, we will present responses observed commonly across all children, including those with developmental disabilities. Most of the cases I was given during patrol duty immediately after the disaster involved regression: symptoms such as being unable to leave their mother's side, being unable to sleep alone, being afraid of darkness, and urinating at night were observed^{2), 3)}. The most basic form of advice in this situation is careful explanation and normalization. To children who have undergone an experience such as this, regression is a very natural response, and is merely a transient return to a more childlike state. I often told mothers that this wasn't a strange response and that it wouldn't last long, and I decided to simply observe and monitor the progress of these cases. Afterward, I continued to visit these individuals in evacuation camps or their own homes, and nearly all cases resolved themselves over time.

(2) Hyperarousal

During my visits to evacuation camps and schools, I observed several children who appeared to constantly be in a state of high spirits. They spoke loudly, moved broadly, angered easily, and were quite sensitive to stimuli around them. This state of hyperarousal is, in fact, a normal defensive mechanism that involves overcharging the nervous system to protect the body in unfamiliar or unpredictable situations. If the state persists for long after the danger has passed, it can cause significant issues in daily life; however, as schools reopened and their lives returned mostly to normal, so did these children.

(3) Re-Experiencing/Intrusion

Re-experiencing/intrusion refers simply to what is commonly known as a "flashback," where a traumatic experience is replayed in one's memories, along with all the associated sensations. If the child in question is at an age at which they will have developed sufficient linguistic ability to do so, they will usually express their discomfort verbally and ask adults around them to listen to what they have to say, thereby addressing the issue. On the contrary, children who are too young to possess this linguistic capacity will recreate their experience through what is known as posttraumatic play. Posttraumatic play is a symptom in which a child who has undergone a traumatic experience will repeatedly re-enact that experience in play. After the disaster, I saw many children playing "earthquake games," "tsunami games," and "evacuation games." In a matter of moments, most of

these children had lost many things quite dear to them to the tsunami, right before their very eyes. I believe that by remembering and recreating scenes similar to their disaster experiences in their play, they were arranging and organizing their memories and experiences.

2. Responses Observed in Children with Developmental Disabilities

Table 1 summarizes the reactions observed in children with developmental disabilities. Many of the responses were understandable given these children’s disability characteristics and cognitive impairments. Anxiety and hyperesthesia increased owing to the collapse of their daily lives, causing frequent panic attacks that then led to self-harm and other injuries. I also observed children detecting the intermittently occurring aftershocks very quickly and becoming quite afraid. As some of these children experienced food shortages after the disaster, every time an aftershock occurred, I saw some of them remember the pain of their hunger and quickly eat whatever was nearby. I also observed obsessive-compulsive behaviors intended to dispel anxiety, such as repeatedly asking their family if things were “okay” and checking their belongings many times before doing anything. The tsunami had washed away all of their belongings, and power outages made playing videogames and so on impossible. Under such circumstances, it was no doubt quite difficult for these children to reorganize their confused thoughts and moods. In a desperate attempt to adapt to their surroundings, I saw some children obsessively helping adults, lining up at storefronts even though their family had already purchased all the necessary supplies.

I believe that intellectual ability affected the reactions these children displayed. Let us examine the days immediately after the disaster. I saw some children with intellectual disabilities continue to sleep soundly, without so much as a trace of confusion on their faces, almost as if they had given up. Others wrapped themselves up in their blankets to block out the outside world and protect themselves ⁴⁾. It seems that there was less confusion when children were in familiar places (home, relatives’ homes, etc.) rather than in shelters. Perhaps under nearly unrecognizable circumstances, as almost all lifelines had been disrupted, cutting oneself off completely from external stimuli may actually have made what should be done clearer. On the contrary, while children with mild cognitive impairment did understand that what was happening was not some normal event, they had trouble imagining just what difficulties the future would hold. It is quite likely that after being exposed to different media sources and observing others around them becoming upset, these children’s fear and anxiety also increased.

Table 1: Symptoms Seen in Children with Developmental Disabilities

Hyperesthesia	<ul style="list-style-type: none"> ▪ Sensitive to shaking and would react immediately. Exaggerated behavior. ▪ Sensitive to noise, and would quickly cover their ears. ▪ Extremely picky eaters, wouldn’t eat food in the camps. Lost weight.
Disruption of habits	<ul style="list-style-type: none"> ▪ Unable to use the bathroom freely, would often end up constipated. ▪ Would wet the bed, and some began wearing night diapers. ▪ Would talk in their sleep, and began sleeping much less.
Physical symptoms	<ul style="list-style-type: none"> ▪ Continuous vomiting and diarrhea, grew weak. ▪ Chronic illnesses like atopic dermatitis or bronchial asthma worsened. ▪ Alopecia areata of unknown cause.
Fixations	<ul style="list-style-type: none"> ▪ Immersed themselves in videogames all day long. ▪ Became unable to throw things away. ▪ Started pulling out their hair or eyebrows.
Self-harm and harmful behaviors	<ul style="list-style-type: none"> ▪ Self-harm behaviors like hitting their head against things worsened. ▪ Easily angered, and would use violence if scolded.

3. Cases

(1) Case 1

Twelve-year-old boy. Was regularly being seen at a clinic for autistic spectrum disorder (ASD). As a child, he was sensitive to noise, and would often cover his ears if something unexpected happened around him. After starting school, he had trouble adjusting to group settings, experienced bullying, and had irregular attendance. When at home, he would immerse himself in videogames or his computer.

Despite not living in an area that was directly struck by the tsunami, his house was partially destroyed, and it became difficult for him to continue living there. He was evacuated to the gymnasium of a nearby school, but he became quite noisy, and his family found it difficult to even find a place to sleep. For some time, he just wrapped himself up in his blankets to drown out external noise, but eventually, he began walking around and refused to stay inside the gymnasium. He monopolized a relief-supply videogame console left in the shared space and spent nearly every moment clinging to it. A middle-aged man encouraged him to give others a turn, but he suddenly started yelling and became violent, causing a scene. Eventually, he and his family returned to their half-destroyed home cut off from lifeline services.

(2) Case 2

Nine-year-old girl. Was being seen at a rehabilitative institution for ASD with intellectual disability. She had very strong fixations regarding her possessions. She would only eat with specific utensils and would only wear specific clothes on specific days. She had a set of objects she would take with her when going out. She almost never went into severe panic, and as long as her fixations were not disrupted, it was not difficult for others to work with her.

During the disaster, the tsunami reached up to her house, and with her family, she evacuated to a nearby high area. She watched silently as the house she had lived in all her life was destroyed by the tsunami. While she evacuated to a camp for a time, she quickly retreated from the noisy environment there, and eventually began to stay at a relative's house that had only suffered slight damage. Only a few days afterward, she began to arrange her favorite objects around her in very particular ways, and before sleeping, would repeatedly check their number and placement. Further, she became unable to throw away things like empty snack bags and would cry out to stop her family from doing so. These behaviors continued for some time after leaving the evacuation camp, but once she returned to school and her life stabilized, they subsided.

(3) Case 3

Ten-year-old boy. Was being seen at a clinic for attention-deficit/hyperactivity disorder (ADHD). He was quite active and impulsive, and as a child, would often get lost. After starting school, he was nearly constantly in conflict with his classmates. He began to be seen at a specialist clinic, and in addition to pharmacotherapy, his family was provided with certain support measures. On weekends and holidays, he would go to lessons with his father, and his overall family relationships were good. His day-to-day life was mostly peaceful.

While the tsunami did reach his house, because his family had evacuated quickly, he did not actually witness it. His father's workplace was hit by the tsunami, and his status was unknown. The radiation fallout forced his family to move and him to transfer schools to an entirely new prefecture where he knew no one. After evacuating, he began to become physically and verbally aggressive with his mother and began to sleep very little. He became loud and physical at school, refused to listen to the teacher, and was continually getting into trouble with his classmates. After receiving significant pharmacotherapy, including antipsychotics, and after participating in a memorial service in his hometown, his physical and verbal aggressiveness subsided.

4. Actual Responses

During the Great East Japan Earthquake, the Ministry of Health, Labour, and Welfare coordinated the dispatch of mental health care teams at the request of affected municipalities. These teams comprised psychiatrists, nurses, psychiatric social workers, clinical psychologists, and administrative personnel, and in collaboration with local public health nurse activities, they patrolled evacuation camps and carried out visitations to damaged housing. Children with developmental disabilities who had caused trouble were also targeted by these care efforts, and they received necessary counseling,

prescriptions, and referrals to specialized institutions as needed. Based on experiences from the Great Hanshin-Awaji earthquake, it was already assumed that support for children would be necessary before these teams were dispatched, and many of them included child psychologists. I also made rounds as a child psychologist from within the prefecture and sought to collaborate with teams from other prefectures. There were several other organizations in addition to these mental health care teams that dispatched personnel to the area. The Japan Association of Clinical Psychologists sent school counselors to elementary and middle schools that suffered severe damage⁵⁾, and the Japanese Society for Child and Adolescent Psychiatry dispatched specialists to the three affected prefectures in accordance with their needs⁶⁾. In addition, pediatric neurologists and other specialists were at work in local areas. As we expect to provide similar support in the event of future disasters, I believe we should make an effort to inform children with developmental disabilities and their families about the presence of counseling counters. At the same time, dispatched personnel should discuss disaster support for children with developmental disabilities in order to prepare for future disasters.

The fact that individualized treatment and responses are critical to long-term relationships applies just as much here as it does during normal times. If there is a lot of agitation or excitement, medical staff will provide drug therapy, and after school resumes, it will be necessary to give consideration to education, and further cooperation between the two will be necessary. It is important to imagine what an event with a traumatic experience looks like from the perspective of individuals with particular characteristics and cognitive abilities and build a way for family members and supporters to get a sense of security amidst these circumstances. The major difference from normal times is that families and supporters themselves tend to lose a sense of normalcy during disasters, which can make it difficult for them to cooperate. Therefore, it is necessary to carefully grasp the characteristics of the target child from normal times and to connect with the collaborative organizations.

In parallel with these support efforts, many attempts were made to provide psychological education according to the child's developmental age⁷⁾. In these psychological education sessions, we accurately communicated the actual events and taught children about what could happen in the future and how to deal with it. In addition, it is useful to verbalize disaster experiences in a relationship with others who you trust in a place where you can feel secure. In some children with developmental disabilities, misunderstandings have deepened confusion. There was a case in which a child would repeatedly cause panic at the evacuation center, shouting that they wanted to "Go home!" In this case, his family did not want to show the child their completely destroyed home because of the fear that it would worsen his confusion. After receiving advice from a professional, the family carefully taught the child the relationship between the earthquake and the tsunami and actually went to the site together. Upon doing so, the child realized that their house was "gone," and their panic ceased. In another case, a child whose close classmate had died kept crying every day because he couldn't meet him. In this case, the child was told that his classmate had died in the tsunami, and after conducting a "farewell party" with his class, the child stopped crying.

These cases show that even when children with developmental delays are concerned, as long as one takes the time to provide knowledge appropriate to their abilities, they will be able to deepen their awareness and avoid experiencing unnecessary anxiety.

5. Issues in Evacuation Camps

Most of the individuals who needed to be evacuated were sent to elementary and middle schools in their neighborhoods. These evacuation camps were filled with people of all ages, all of whom were trying their best to survive in the chaotic circumstances they'd been placed in. I saw delirious elderly individuals wandering around and middle-aged men drinking through the night. Families of children with developmental disabilities mostly realized that it would be difficult to live quietly through such circumstances, and many left evacuation facilities as quickly as possible. These individuals chose to live in their greatly damaged houses or cars and experienced great difficulty as lifelines to their residences remained cut off. As nearly all relief supplies were sent to evacuation centers, they generally did not reach those who evacuated to their homes or cars. In this situation, members of the community, such as teachers and welfare workers, stepped up to carry supplies to these individuals.

Table 2 lists the status of children enrolled at Ishinomaki Support School who were forced to evacuate from their homes (as of June 23, 2011)⁸⁾. While this population includes a large number of children without any developmental disabilities, this figure makes it clear that families raising such children usually cannot choose to evacuate to evacuation camps. Arai et al. conducted a needs survey for evacuation shelters in the event of a large-scale disaster for parents at a support school in Ibaraki Prefecture and reported similar results⁹⁾.

In terms of a countermeasure against this situation, because these individuals are likely to become anxious in the face of unfamiliarity, the ideal setting would be an evacuation camp that attempts to provide an environment slightly closer to that of their everyday lives. Although there is a plan to make a local support school a welfare shelter for children with disabilities, there is still much room for debate. In the event of a large-scale disaster, it is not always possible to take flexible measures according to the characteristics of each child. Therefore, a system for accepting external professionals should be put in place during normal times, and in an emergency, it should be a base to support the evacuation life of children with developmental disabilities.

Table 2: Evacuation Status of Ishinomaki Support School Students

Living situation	Elementary	Middle school	High school	Total
Relatives' house	8	2	3	13
Apartment or rented house	2	2	3	7
Evacuation camp	1	2	2	5
Moved elsewhere	0	0	3	3
Facility	1	0	0	1
Emergency temporary housing	1	1	1	3
Total	13	7	12	32

As of June 23, 2011

(Miyagi Prefecture Ishinomaki Support School. What We Have Learned from the Great East Japan Earthquake. Suzuki Printing Press, 2012. Reprinted with permission.)

6. Relationships with Their Communities

Family members of children with disabilities agree on the importance of connecting with the community. When a child's developmental bias is mild, the family is generally reluctant to inform others, but in an emergency, it becomes more necessary to seek the understanding of those around them. If something was not done in normal times, it is difficult to make it happen in an emergency, and I realized the importance of creating a network in normal times. Children with disabilities also live in the community, and it is necessary to anticipate what kind of support is needed during normal times. In fact, the number of people who want to use welfare services such as after-school care has increased since the earthquake. It was also reported that various family associations and social network services such as Twitter and Mixi were useful as sources of connections.

In addition, there were opinions that "support books" were useful. These are a record of information to convey one's characteristics and symptoms to a person who first encounters a child with various disabilities¹⁰⁾. This will enable them to receive consistent education and support for a stable life in the community. Many children with developmental disabilities receive daily medical attention from their general practitioners, who already have information about their background and characteristics. However, after the earthquake, many children found themselves in unfamiliar situations and experienced physical symptoms such as loss of appetite and vomiting. Moreover, in such situations, these children were not always able to see their family doctors, and were tended to by unfamiliar dispatched doctors. The support book is useful for familiarizing new doctors with these children's characteristics, which facilitates smooth medical treatment. There is room for reconsideration about the places to consult and visit the hospital on a daily basis. In Japan, the number of specialists who can deal with developmental disorders is currently insufficient¹¹⁾. In areas where there are few specialists, it is not uncommon to visit specialists far from home. From the perspective of raising children in the community, it was also necessary to strengthen ties with nearby non-specialists with the support of distant specialists. On the medical

side, it was considered more important for general pediatricians and psychiatrists rather than training specialists to be able to deal with children with developmental disabilities.

7. Emergence of Developmental Disability Cases

During this disaster, I saw cases involving children who had experienced no problems prior to the earthquake, but pre-existing disorders were rerealed because of the harshness of evacuation life. Until then, these children were accepted as “unique” in their communities, but suddenly the protective function of these communities collapsed. Unable to stay calm at evacuation camps, these children were criticized by the adults around them for being “noisy,” or were told “Please, just do something,” which sometimes led to patrol consultations. As I conducted multiple interviews, I began to hear stories that told of certain biases in the development of these children. However, for many cases that led to consultations, we avoided mentioning developmental biases during our short-term involvement. For cases where our involvement continued past the acute phase, we made an effort to gradually tell families that developmental disabilities were one of the causes of their children’s environmental maladaptation.

One characteristic of the medium- to long-term period among community mental health services was that we began to receive a large number of counseling cases from the families of shut-ins in their 30s and 40s. During my home visits and interviews with these individuals, I often noticed developmental delays. Many of them had been refusing to go to school since they were in elementary and junior high school, and even after graduating from high school, they could not get regular jobs and stayed at home for a long time. During this earthquake, they were forced, almost without exception, to evacuate, enter the community, and interact with local residents. However, communication could not proceed smoothly, and their evacuation lives proved very stressful. Most of the parents of such individuals were in their 50s and 60s, and until now they had simply lived alongside them, resigned to the feeling that there was no help for their situation. However, I believe that when confronted with the disaster, these parents became anxious about what would happen to their children after they were no longer around to care for them. Thus, I believe that these cases, too, emerged as a result of the disaster.

8. Conclusion

Their innate characteristics and cognitive tendencies make it quite difficult for children with developmental delays to tolerate ambiguity, and many of them live in a state of near-constant anxiety. Their restlessness and strong fixations toward seemingly minor things are responses that stem from their perceived lack of safety and security. These children have their own unique objects and behaviors, and when anxiety arises, they immerse themselves in them to wipe it away and to reset their emotional state. Unexpected traumatic experiences can destroy in seconds the fortresses of calm and security they have slowly built up for themselves. At the same time, the objects and behaviors to which they often turn to wipe away their anxieties are also taken from them, and they can fall into a deep, indescribable despair. Their lives after these events become nothing more than a singular effort to rebuild a world in which they feel safe. Repeated explanations tailored to the characteristics of the child and experiences through which they may gain some small measure of reassurance become necessary.

As a final thought, I would like nothing more than for what I have written here to benefit the support of children with developmental disabilities during disasters.

<References>

- 1) Tatsuya Koeda: Research on the Discovery and Response System of Children with Mild Developmental Disabilities and the Development of Their Manuals. 2006 Health Science Research Project, 2007.
- 2) Naru Fukuchi, Mizuho Hayashi: The Current State of Mind of Children in the Disaster Area. *Children's Spirit and Nerves*, 2011; 51: 126–132.
- 3) Naru Fukuchi: What the Earthquake Gives to the Nursing Environment. *Child Abuse and Neglect*, 2012; 14: 14–19.
- 4) Mikawa Takahashi: Survival of a Self-Closing Family After the Great Earthquake. First Edition, Grape Company, 2012.
- 5) Mariko Okumura: About the Activities of the Great East Japan Earthquake Psychological Support Center. *Journal of the Japan Clinical Psychologist Association*, 2012; 72: 33–34.
- 6) Kiwamu Tanaka, Toru Yamazaki: Child Care in the Great East Japan Earthquake-Current Situation and Challenges. *Child and Adolescent Psychiatry and Its Proximity Area*, 2012; 53: 59–76.
- 7) Yoshiki Tominaga, Mitsuko Miura, Sho Yamamoto, et al.: Support Class for Children's Minds After a Large-Scale Disaster. *Traumatic Stress*, 2012; 10: 11–15.
- 8) Miyagi Prefecture Ishinomaki Support School: What I Learned from the Great East Japan Earthquake. Suzuki Printing Co., Ltd., 2012.
- 9) Hideyasu Arai, Ryuta Kanamaru, Akira Matsuzaka, et al.: Disaster Prevention Handbook for Children with Developmental Disabilities. First Edition, Creates Kamogawa Inc., 2012.
- 10) Tetsuo Murakawa, Hiroaki Honma: Autism Rehabilitation Chart: Achieving Continuous Support. First Edition, Akashi Shoten, 2010.
- 11) Hidetaka Tanaka: About the Current State of the Medical Doctor Training Business for Children's Minds in Japan. *Children's Mind and Body*, 2008; 17: 131–135.

(Naru Fukuchi: Support for Developmentally Disabled Children in Disasters: Experiences during the Great East Japan Earthquake. Published in *Advances in Developmental Disability Medicine*, Vol. 25. Diagnosis and Treatment Corporation, 2013: 36–42.)