

The Challenges and Difficulties of People with Disabilities from the Perspective of the Social Model of Disability; The 2014 ICF-based Checklist of Functioning Difficulties in Times of Disasters in Sendai City in Miyagi Prefecture

Anna MATSUKAWA¹ and Shigeo TATSUKI²

¹ Organization for Research Initiatives and Development, Doshisha University.

² Department of Sociology, Doshisha University.

In order to identify challenges and difficulties experienced by people with disabilities (PWD) and their families during the 2011 Great East Japan Earthquake disaster, 41 impacted PWD and their supporters were invited to a grass-roots assessment workshop on October 14th 2013. The workshop participants were from 16 different disability organizations catering for people with visual, auditory, speech, physical, mental, developmental/intellectual disabilities as well as for people with internal organ disorders and one for those suffering with paraplegia and quadriplegia. Following the Total Quality Management method, the participants sorted the difficulty and challenge cards according to their affinity. This experiences were adapted to classify as functional needs in everyday life by International Classification of Functioning, Disability and Health (ICF). Based on this results, ICF-based Checklist of Functioning Difficulties in Times of Disasters was constructed and it was employed in a social survey conducted in Sendai city from January to February, 2015. The questionnaire was mailed to 3,005 PWD and 1,083 responded.

Keywords : *he Great East Japan earthquake, people with special needs in times of disaster (PSND), International Classification of Functioning, Disability and Health (ICF), social model of disability*

1. Introduction

Japan is a country that is taking the lead in promoting evacuation and sheltering assistance for people with special needs (PSND) in times of disasters. In 2004, Japan experienced a series of natural disasters such as the Niigata-Fukushima flood (July), the many typhoons that hit Japan include Typhoon Tokage (October), and the Niigata Chuetsu earthquake (October). The Japanese Cabinet Office established a committee on “Communication Disaster Information and Evacuation/Sheltering Assistance for the Elderly and Other Members of the Population during Heavy Meteorological and Other Disasters” following the 2004 series of disaster damage. This committee published the first guideline in March 2005 which was called “Evacuation/Sheltering Assistance Guideline for People with Special Needs in Time of Disaster.” The committee continued working. So, they revised the guideline in 2006 and also published a report on the guideline in 2007. The committee used the term *saigai-jakusha* or “disaster-vulnerable people,” however, that term has been replaced since the publication of guideline by *saigaiji-youengosha* or “people with special needs in times of disaster (PSND).” This change was based on a paradigm shift in disability studies, from “medical model of disability” to “social model of disability”¹⁾.

The paradigm shift of disability studies has been made possible by the redefinition of disability by PDW themselves. The new definition of disability is based on the perspective that disability is socially generated. The medical model of disability is a one way causal model. The individual physical condition (impairments) cause activity limitations and participation restrictions (disabilities), and these cause social disadvantages (handicaps.) The solution proposed by the medical model is

medical intervention for individual impairments. The social model, on the other hand, assumes interactive relationships between individual impairments and social factors. In other words, individual impairments do not lead to disabilities, and disabilities are caused by society when it fails to give equivalent attention and accommodation to the needs of individuals with impairments. That being the case, society has a responsibility to relieve disabilities^{2,3)}. There is no systematic research on the life and activities of PSND after disasters from a perspective of the social model of disability.

The International Classification of Functioning, Disability and Health (ICF) is a usable tool for conducting research based on the social model of disability. ICF was accepted by WHO in 2001 as a response to the paradigm shift in disability studies. In contrast to the International Classification of Impairments, Disabilities and Handicaps (ICIDH), ICF contains environmental factors and places more attention on the interactive relationships between individual impairments and social/environmental factors. By using ICF, it becomes possible to study PSND’s activity limitations and participation restrictions instead of their impairments³⁾.

In contrary, studies about PSND are very weak. Most of studies are focused on specific impairments or handicaps, such as mechanical ventilation. This means many studies of PSND are still based on medical model. It is necessary to study about PSND from social model.

(1) 2013 TQM (Total Quality Management)-style workshop
To analyse the evacuation and sheltering of PSND from a social model perspective by using ICF, a grass-roots workshop was held in Sendai city on October 14th 2013. There were 41

participants from 16 different disability organizations catering for people with visual, auditory, speech, physical, mental, developmental/intellectual disabilities as well as for people with internal organ disorders and one for those suffering with paraplegia and quadriplegia. They were asked to report on post-it-cards what challenges and difficulties they encountered during each of the disaster process phases from 0 to 10 hours, 10 to 100, 100 to 1,000 and to 1,000 to 10,000 hours after the Great East Japan Earthquake. Following the Total Quality Management method that was originally introduced in life recovery assessment workshops for the 1995 Kobe earthquake survivors, ideas and opinions were sorted according to their affinity.

The qualitative data obtained in the workshop was quantified using the dual scaling method and analyzed quantitatively. The dual scaling method is a technique for performing =quantification based on the principle of internal consistency and the qualitative data without external criteria. In this study, the data was converted to reaction type data in multiple-choice form. The various opinion cards were stored in rows, ICF categories were stored in columns, and values used dummy data (consisting only of 1 or 0).

As a result, this research showed how society needs to handle the situation PSND faces in each time phase (Figure 1). During Phase 1, society needs to figure out how PSND smoothly evacuate and find available shelters. The society has to keep some spaces for PSND in shelters. Also society needs to prepare a way for them to reach smoothly the things that they need such as information about welfare shelters, medicine, daily needs and any other support services. During Phase 2 and 3, they had to spend time living in an inconvenient way in shelters or their own

affected home. Society has to provide services that encourage them to take care of themselves even at the shelter. When it comes to Phase 4, whereas there is a reduction in the amount of actual needs, mental care and assistance of administrative procedures are still needed. Since the fate of relatives are unknown or the environment has been changed by the disaster, people feel really anxious and sometimes their symptoms become worse. For administrative procedures, not only generous support, but also efforts of the government are required to provide the necessary information at the right times. This results showed ICF can be a useful framework for studies of PSND.

(2) Objectives of Research

The mission of current research is to document empirically the difficulties that PSND experienced during and after the 2011 Great East Japan Earthquake (GEJE) and to make an advocacy in order to reduce disaster risks among them. 2013 workshop study proved the usefulness of ICF as a study framework. However this results cannot be called empirically verified. This means there is a need to conduct quantitative study.

2. Method

(1) Sample

The population size for each registry was 31,668 for physical disability certificate, 7,314 for rehabilitation certificate for children, 7,889 for mental disability certificate and 8,211 for those with intractable diseases specified by the National Government. 3,005 individuals or 5 % of those who were registered in these registries were randomly sampled for the current study. Because age distribution of those with physical

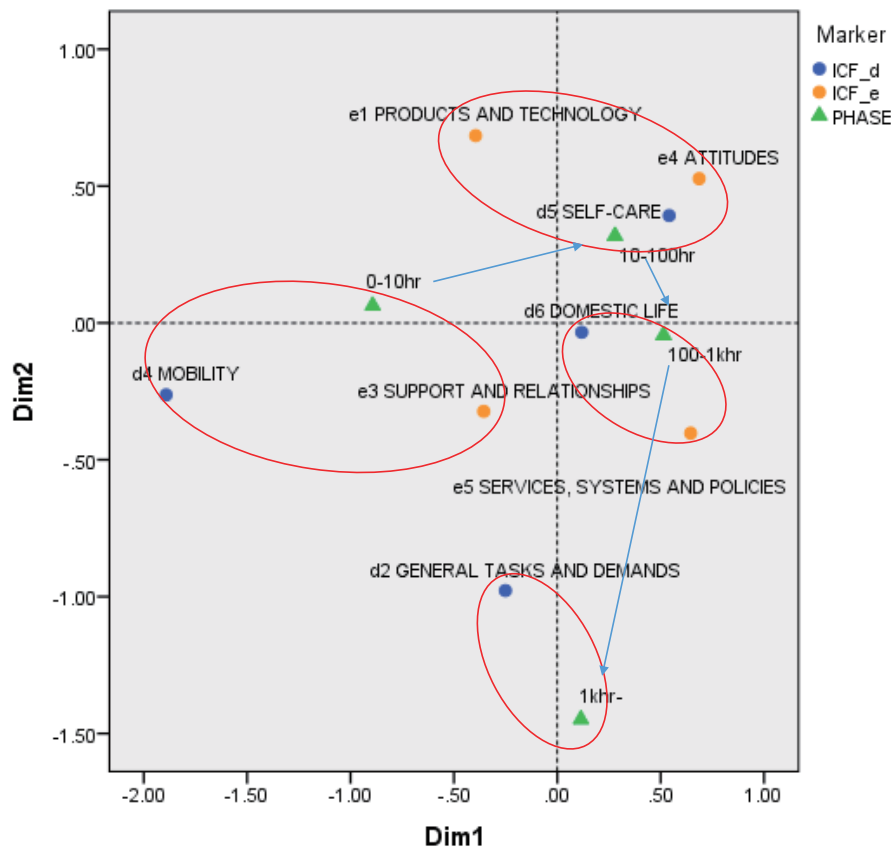


Fig. 1: The result of correspondence analysis

disability certificate are heavily skewed after 65 years old, 1:2 ratio sampling method was used in order to better represent those younger than 65 years old.

(2) Instruments

Check List for Functioning Difficulties in Times of Disasters was developed for the current study. The checklist is the direct product from the 2013 workshop study. The checklist consists of 31 ICF-like items, each of which asks a “yes-no” question whether a respondent experienced any difficulty in either

selected 5 “Activities and Participation” or all 5 “Environmental Factors” categories. The checklist respondents were asked to respond to 31 ICF items during each of the disaster time phases 4,5) from 0 to 10 hours, 10 to 100, 100 to 1,000 and to 1,000 to 10,000 hours after GEJE. Also physical and house damage items were included in the questionnaire.

(3) Analysis

Physical and house damage including relocation experiences

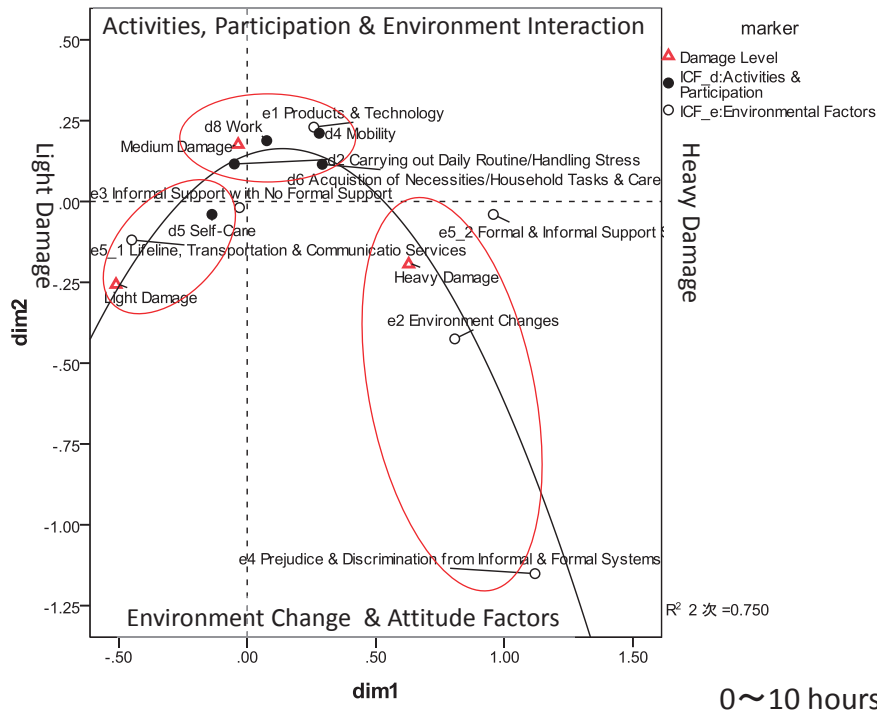


Fig. 2: Corresponding Analysis Results of ICF-by-Disaster Damage (0~10hours)

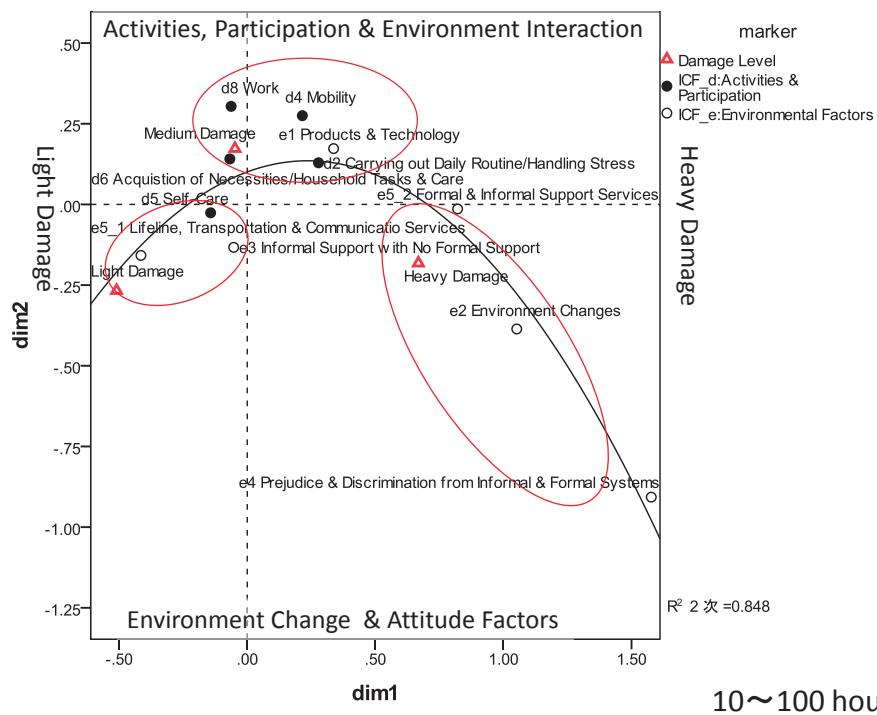


Fig. 3: Corresponding Analysis Results of ICF-by-Disaster Damage (10~100hours)

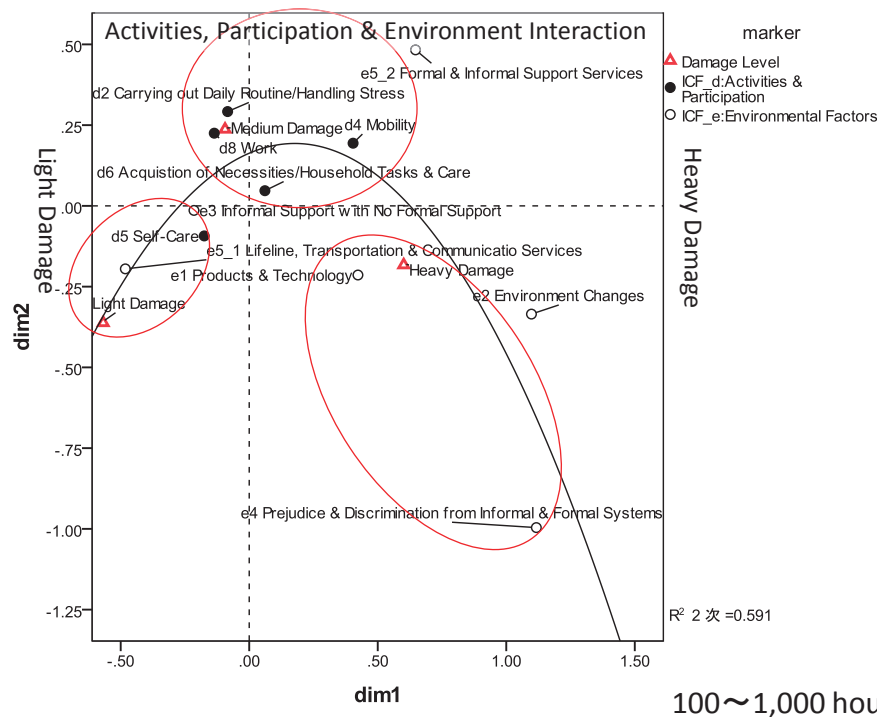


Fig. 4: Corresponding Analysis Results of ICF-by-Disaster Damage (100~1,000hours)

were cluster-analyzed and light, medium and heavy damage categories were formed. Damage-by-ICF cross-tabulated matrices were then created. Each matrix row (ICF) and column (damage) category associations were graphically plotted using correspondence analysis method⁶⁾ (Fig. 2~4).

3. Results

As a result of each time phase, light, medium and heavy damage categories were plotted left to right on the horizontal axis while sets of damage and functioning difficulty categories were clustered in a \cap shape in Fig. 2 to 4: 1) light damage was associated with lifeline and other service disruptions (e5_1○) which were closely associated with self-care (d5●) difficulties and with informal support from family and neighbors (e3○). 2) Medium damage was characterized by work (d8●) and daily routine (d2●) disruptions and also by inaccessibility to formal and informal support services (e5_2○), to daily necessities (d6●), and by mobility problems (d4●). 3) Heavy damage seemed to have caused severe environmental changes and a lack of goods and products. At its extreme level, however, issues on attitudes in formal and informal systems were displayed. This seemed to be uniquely experienced by PWD in times disasters.

4. Discussion

From these findings, the following two points were proposed as effective policies: 1) For those with low to medium damage, PWD functioning difficulties arose from lifeline and related services disruptions. Reasonable accommodations are needed in “Activities & Participation” domain, and more specifically in its d2, d4, d5, d6 and d8 categories. Communities’ sharing PWD sensitive/personal information, institutionally ensuring accessibility and everyday collaborating for DRR are essential to achieve this goal. 2) Historical/ institutional constraints surfaced among heavily damaged PWD. They are the root

causes that require emancipatory practices through strength building in individual PWD and in their communities as well as through such social actions as an advocacy for and mainstreaming of PWD.

REFERENCES

- 1) Tatsuki, S. (2013). “Old Age, Disability, and the Tohoku-Oki Earthquake,” *Earthquake Spectra.*, vol. 29, pp. S403–S432.
- 2) Oliver, M (1990). *The politics of Disablement*, London, UK: Macmillan.
- 3) Hoshika, R (2007). *Shogai toha Nanika (障害とは何か)*, Tokyo, Japan: Seikatsu-Shoin.
- 4) Hayashi, H. (2003), *Inochi wo Mamoru Jishin Bousaigaku (いのちを守る地震防災学)*, Tokyo, Japan: Iwanami.
- 5) Kimura, R. Tomoyasu, K and Yajima, Y. (2014), "Reconstruction Progress Situation of the Third Year from the Great East Japan Earthquake by Victims' Questionnaire Survey : Focusing on Sense of Stagnation in Disaster Reconstruction and Ambivalence in Housing Reconstruction" *Journal of Social Safety Science*,(22-24), 233-243.
- 6) Nishisato, S. (1980) *Analysis of Categorical Data: Dual Scaling and Its Applications*, Toronto: University of Toronto Press.