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The Experiences of People with Functional Needs in Times of Disasters

Results from the 2013 Sendai Grass-roots Assessment Workshop

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ABSTRACT

In order to identify functional needs of people with disabilities (PWD) during the 2011 Great East Japan Earthquake, 41 impacted PWD and their supporters were invited to a grass-root assessment workshop on October 14, 2013. The workshop participants were from 16 different organizations for people with visual, auditory, speech, physical (including paraplegia and quadriplegia), mental and developmental/intellectual disabilities as well as for people with internal organ disorders. They were asked to report on post-it-cards what challenges and difficulties they encountered in each disaster process phase from 0 to 10 hours, 10 to 100, 100 to 1,000, and 1,000 hours and later after the 2011 disaster. Following the Total Quality Management (TQM) method, the participants themselves sorted/grouped the difficulty and challenge cards according to the affinity. There empirical clustering processes led to form a hypothesis that experienced difficulties could be understood according to and explained by International Classification of Functioning, Disability and Health (ICF). Thus was formed an ICF-by-disaster-time-phase cross-tabulation data. Its correspondence (dual scaling) analysis revealed quantitatively the affinity association between ICF (row) categories and their corresponding disaster phase (column) categories. The results indicated that "mobility" and "products and technology" were the critical ICF category during the first 10 hours, "self-care" and reasonable accommodations in "attitudes" of the society arose during the next 10 to 100 hours, "domestic life" tasks as well as utilizing "services, systems and policies," and "general tasks and demands" especially dealing with psychological stress characterized the phase after 1,000 hours.

1. INTRODUCTION

Japan is a country that is taking the lead in promoting evacuation and sheltering assistance for the elderly and PWD in times of disasters. In 2004, Japan experienced a series of natural disasters such as the Niigata-Fukushima flood (July), Typhoon Tokage (October), and the Niigata Chuetsu earthquake (October), in each of which higher mortality rates were recorded among the elderly and PWD. Therefore, the Japanese Cabinet Office established a committee on "Communication of Disaster Information and Evacuation/Sheltering Assistance for the Elderly and Other Members of the Population during Heavy Meteorological and Other Disasters". This committee published the Evacuation/Sheltering Assistance Guideline for People with Special Needs in Time of Disaster on March, 2005. The committee continued working: they revised the guideline in 2006 and also published a report on the guideline in 2007. The term saigai-jakusha or disaster vulnerable people has been customarily used since the 1995 Kobe earthquake. The 2005 and the following committees coined the new term saigaiji-youengosha or "people with special needs in

times of disaster." The development of these new terminologies was based on a paradigm shift in disability studies, from "medical model of disability" to "social model of disability" (e.g. Tatsuki, 2013).

The paradigm shift of disability studies has been made possible by the redefinition of disability by PWD themselves. The new definition of disability is based on the perspective that disability is socially constructed. The medical model of disability, an old paradigm, is a one way causal model. The individual physical condition (impairments) causes 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 new 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 reasonable accommodation to the needs of individuals with impairments. Society has therefore a responsibility to relieve disabilities (e.g. Oliver, 1990; Hoshika, 2007). In the field of disaster research, only a very few studies have focused on people with disabilities from this new social paradigm of disability (Tatsuki, 2013).

The International Classification of Functioning, Disability and Health (ICF) is an international standard that describes and measures health and disability based on the integrative model that accommodate both medical and social model of disability (WHO, 2002). 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 includes environmental factors and places more attention on the interactive relationships between individual impairments and social/environmental factors. By using ICF, it becomes possible to operationally specify what types of "special needs" the PWD experienced and more importantly what types of "functional supports" are needed in the interactive relationships between the PWD and their environment in times of disasters. This paper, therefore, proposes the term saigaiji-seikatsu-kinou-youshiensha or "people with functional needs in times of disasters" (Kailes & Enders, 2007). This term is more operationally specific and therefore implementation-oriented rather than "disaster vulnerable people", which neglects the social interaction aspect of why disability is constructed, or "people with special needs in times of disasters", which is more conceptually vague and thus less prescriptive to emergency actions.

The purpose of the current study is two-fold: to document the difficulties that the PWD experienced during and after the 2011 Great East Japan Earthquake and to analyze their functional needs from a social model of disabilities. The study draws on qualitative accounts provided by 41 PWD in Sendai city about their life difficulty experiences in a TQM

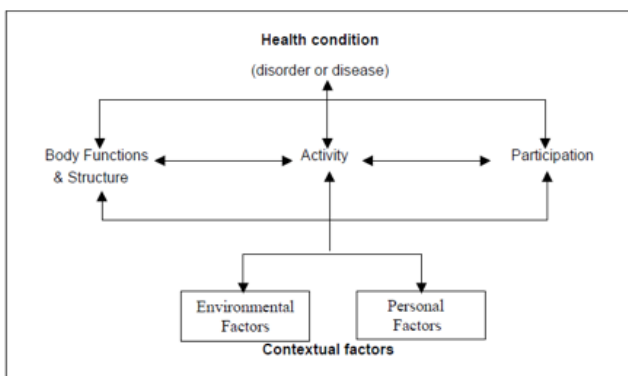
(Total Quality Management)-style workshop.¹ The workshop data was classified by ICF and by disaster time phase (Hayashi, 2003; Kimura et al., 2014). The "ICF category by disaster time phase" cross-tabulation was then analyzed by dual scaling (also known as correspondence analysis) method (Nishisato, 1980), which yielded particular sets of a given disaster time phase and corresponding specific functional needs. The research findings indicated how PWD-in-environment interactions needed to be accommodated

2. METHODOLOGY

2.1. Participants

On October 14, 2013, a grass-roots assessment workshop was held in Sendai city. A total of 41 PWD participated in the workshop, recruited from 16 different organizations catering for people with visual, auditory, speech, physical (including those suffering with paraplegia and quadriplegia), and mental, developmental/intellectual disabilities as well as for people with internal organ disorders. They were asked to report on post-it cards what challenges and difficulties they encountered during each of the disaster time phases (Hayashi, 2003; Kimura et al., 2014) from 0 to 10 hours, 10 to 100, 100 to 1,000 and 1,000 to 10,000 hours after the Great East Japan Earthquake. Following the TQM method originally introduced in life recovery assessment workshops for the 1995 Kobe earthquake survivors, ideas and opinions were sorted according to their affinity.

Figure 1: Conceptual diagram of ICF. (WHO 2002, p.9)



2.2 Instrument

ICF is a classification of health and health-related domains as shown in Figure 1 above and is the international standard to describe and measure health and disability (WHO, 2002). Based on the social model of disability, ICF views disability and functioning as outcomes of interactions between health conditions and contextual factors that include environmental and personal factors, such as

gender, age, coping styles, and social background. ICF identifies three levels of human functioning at the level of body (physiological functioning and impairments), the whole person (activity, activity limitation participation and participation restriction), and the whole person in a social context (physical, social and attitudinal environment). As a measurement instrument, ICF postulates 4 constructs (or domains) such as Body Functions (b), Body Structure (s), Activity and Participation (d), and Environmental Factors (e), each of which is operationally defined in a hierarchical fashion (e.g., Chapter, Second level, Third level, and Fourth level where Chapter being the most abstract construct and the following levels operationalizing it by more detailed nomenclature). Table 1 below illustrates the complete list of chapters in ICF. For this study, each statement that the workshop participants produced was considered using the ICF framework and was coded at all four levels.²

Table 1: Chapters of ICF (WHO 2002, p16).

Body	
Functions	Structures
Mental functions	Structure of the nervous system
Sensory functions and pain	Eye, ear and related structures
Voice and speech functions	Structures involved in voice and speech
Functions of the cardiovascular, haematological, immunological and respiratory systems	Structure of the cardiovascular, immunological and respiratory systems
Functions of the digestive, metabolic and endocrine systems	Structures related to the digestive, metabolic and endocrine systems
Genitourinary and reproductive functions	Structures related to the genitourinary and reproductive systems
Neuromuscular and movement-related functions	Structures related to movement
Functions of the skin and related structures	Skin and related structures
Activities and Participation	
Learning and applying knowledge	
General tasks and demands	
Communication	
Mobility	
Self care	
Domestic life	
Interpersonal interactions and relationships	
Major life areas	
Community, social and civic life	
Environmental Factors	
Products and technology	
Natural environment and human-made changes to the environment	
Attitudes	
Services, systems and policies	

2.3 Procedure

The workshop data was classified by ICF and by disaster time phase. This produced an "ICF category by disaster time phase" cross-tabulation. The association among the table row and column categories was then quantitatively analyzed by dual scaling (also known as correspondence analysis) method (Nishisato, 1980), a quantification technique based on the principle of internal consistency.

Table 2: Grass-roots assessment workshop results

ICF Category	Disaster Time Phase								Row Total	
	0 – 10 hours		10 – 100 hours		100 – 1,000 hours		1,000 hours +			
d1: Learning and Applying Knowledge	0	(0%)	1	(1%)	0	(0%)	0	(0%)	1	(0%)
d2: General tasks and demands	12	(10%)	11	(6%)	7	(7%)	9	(21%)	39	(9%)
d3: Communications	0	(0%)	2	(1%)	1	(1%)	1	(2%)	4	(1%)
d4: Mobility	13	(11%)	3	(2%)	0	(0%)	2	(5%)	18	(4%)
d5: Self care	8	(7%)	31	(18%)	15	(15%)	3	(7%)	57	(13%)
d6: Domestic life	31	(27%)	50	(29%)	33	(33%)	12	(29%)	126	(29%)
d7: Interpersonal interactions and relationships	1	(1%)	0	(0%)	0	(0%)	0	(0%)	1	(0%)
d8: Major life areas	0	(0%)	0	(0%)	3	(3%)	1	(2%)	4	(1%)
d9: Community, social and civic life	0	(0%)	0	(0%)	0	(0%)	1	(2%)	1	(0%)
e1: Products and technology	30	(26%)	37	(22%)	13	(13%)	0	(0%)	80	(19%)
e2: Natural environment and human-made changes	1	(1%)	0	(0%)	0	(0%)	0	(0%)	1	(0%)
e3: Support and relationships	12	(10%)	9	(5%)	8	(8%)	4	(10%)	33	(8%)
e4 Attitudes	1	(1%)	3	(2%)	3	(3%)	0	(0%)	7	(2%)
e5: Services, systems and policies	6	(5%)	25	(15%)	17	(17%)	9	(21%)	57	(13%)
Total	115	(100%)	172	(100%)	100	(100%)	42	(100%)	429	(100%)

3. RESULTS

3.1 ICF-by-Disaster Time Phase Cross-tabulation

Forty-one grass-roots TQM-style assessment workshop participants produced 429 statements regarding the life difficulties they experienced after the onset of the Great East Japan Earthquake-procedures of the workshop was described in detail at the footnote on page 2. These statements were first categorized into one of the disaster time phases by the workshop participants themselves.

The statements were then clustered into more summative groupings and each grouping was coded based on the ICF categories. Table 2 below shows frequencies of ICF category (Chapter and Second nomenclature level) by time phase. It was revealed that life difficulties experienced by PWD peaked during the first 100 hours (about 70% of all the reported difficulties) and lasted about 1,000 hours (90% of difficulties collected at the workshop). This suggested that PWD life difficulty experiences during the disaster time approximately corresponded to the time phase when basic functioning of the society had been impacted by the disaster, until emergency relief activities helped to recover the

essential utility, transportation and other critical facilities' basic functioning that took approximately 1,000 hours.

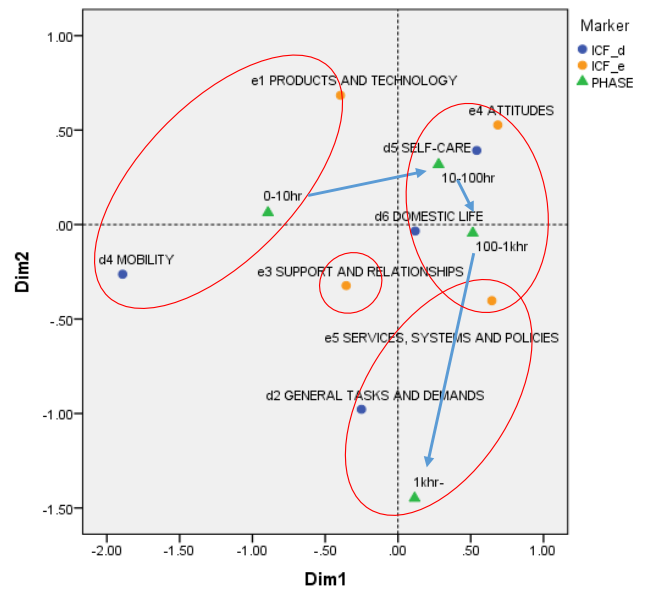
It became clear that PWD did not experience whole range of ICF category-related difficulties equally but specific category-related difficulties were experienced more often than the other. The current study found that all the reported difficulties were classified either in the domain of Activities and Participation or Environmental Factors. The four most reported difficulties in Activities and Participation were in the area of "d6 Domestic Life" (29%) (e.g., acquisition of necessities, household tasks, and caring for household objects), "d5 Self-Care" (13%) (e.g., washing oneself, caring for body parts, toileting, dressing, eating, drinking and looking after one's self), and "d2 General Tasks and Demands" (9%) (e.g., undertaking a single and multiple tasks, daily routine and holding stress and other psychological demands), and "d4 Mobility" (4%) (e.g., changing and maintaining body position, carrying, moving and handling objects, walking and moving, and moving around using transportation). Within the environment factors, the top three most reported life functioning needs were "e1 Products and Technology" (19%) (e.g., medicines, equipment for personal daily living and mobility, and products and technology for communication), "e5 Services, Systems and Policies" (13%)

(e.g., utilities, services for communication, transportation, civil protection, legal and administrative applications, social security, general social support, and health), and "e3 Supports and Relationships" (8%) (e.g., family, friends, neighbors, personal care providers, strangers, health and other professionals).

3.2 Correspondence Analysis of the ICF-by-Disaster Phase Cross-tabulation Table

In order to explore ICF-needs-by-disaster time phase patterns, proportions of ICF categories at each disaster time phase were graphically displayed in Figure 2 below. In order to identify the most characteristic associations of the ICF needs (rows of Table 2) and time phase (columns of Table 2), correspondence (dual scaling) analysis was employed to analyze quantitatively more intricate associations among table 2 row and column categories. For example, ICF category of "d4 Mobility" accounted for less than 4% out of all the reported difficulties (i.e., 18/429). However, it accounts for 11% of the ICF categories if one focuses only to the first 10 hours (13/115) (see also Figure 2). This suggests that there may exist a characteristic relationship between the row category (d4 Mobility) and the column category (0hr to 10 hour). Correspondence analysis produces a two-dimensional plot (or biplot) of row and column category of cross-tabulation data where those characteristic or corresponding row and column categories are placed in proximity in usually a 2 dimensional space (Nishisato, 1980).

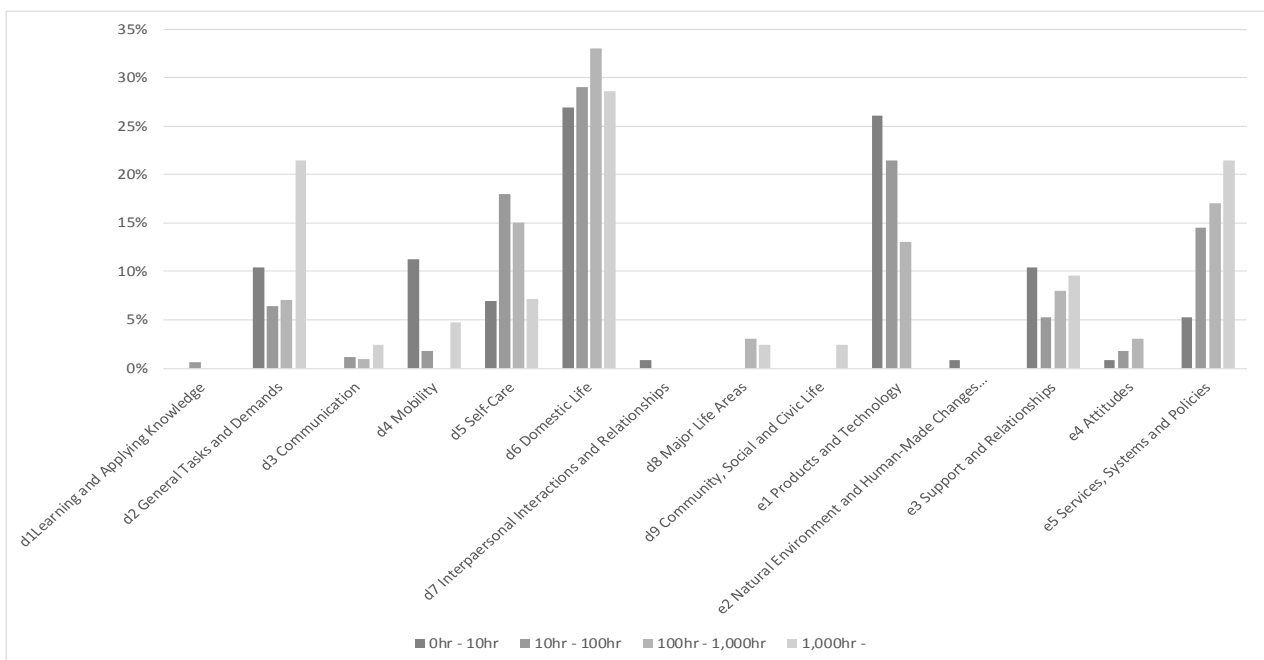
Figure 3: Corresponding analysis results of ICF-by-time phase cross-tabulated data



Note: Those categories with low frequencies (i.e., less than 1%) were excluded from the analysis for robustness and stability of the analysis results.

The result of the correspondence analysis is shown in the Figure 3 above, where 1) four time phases and corresponding ICF category sets were clustered into four groups and 2) characteristic ICF and disaster time phase correspondences were revealed. First of all, the left side cluster shows the most characteristic ICF categories that appeared within the first 10 hours after the earthquake and it included "d4

Figure 2: Proportions of ICF categories by disaster time phase



Mobility" and "e1 Products and Technology." The most life-threatening needs that PWD experienced in this phase were that of mobility. In normal circumstances, PWD can rely on cars, wheel chairs, and other equipment for transportation with the support from family members and their care workers. Most PWD, however, were not able to find the support from the immediate relationships and thus were not able to evacuate to nearby shelters. If they were able to elicit extra help from neighbors and even strangers for mobility support and to move to shelters, they faced life difficulties due to the lack/unavailability of "e1 Products and Technology" such as medicines, equipment for personal daily living and mobility, and products and technology for communication.

The right upper area shows the cluster consisting of two disaster time phases of 10 to 100 hours as well as that of 100 to 1,000 hours. These time phases corresponded with that of sheltering (10 to 100 hours) and of living a life when lifeline and other basic critical facilities were not functioning at normal level. The 10 to 100 hours phase was first typified by "d5 Self-Care" difficulties which included washing oneself, caring for body parts, toileting, dressing, eating, drinking and looking after one's self either at the shelter or at their disaster affected home. These difficulties were accompanied by the continuing lack/unavailability of "e1 Products and Technology" such as medicines, equipment for personal daily living and mobility, and products and technology for communication. The life conditions of PWD were further aggravated by the lack of reasonable accommodation from "e4 Attitudes" in family members, friends, neighbors, shelter authority, personal care providers, strangers, health professionals, society and social norms. The succeeding 100 to 1,000 hours phase was characterized by gradual re-entry into post-disaster normalcy where PWD faced daily chores associated with "d6 Domestic Life" that included acquisition of necessities, household tasks, and caring for household objects and those with "e5 Services, Systems and Policies" (e.g., utilities, services for communication, transportation, civil protection, legal and administrative applications, social security, general social support, and health).

The right lower cluster was characterized by the time phase of 1,000 hours and over and "d2 General Tasks and Demand" which mainly consisted of handling stress and other psychological demands in post-disaster recovery time. Finally, "e3 Support and Relationships" need was situated

in the middle of Figure 3 indicating that there was no peak phase for this category and it was exhibited equally among the four time phases which is also illustrated in Figure 2.

4. CONCLUSION

This study showed how society and PWD themselves needed to handle the situation that PWD faced in each time phase. First, the results indicate that during the first 10 hours, society in collaboration with PWD and their families need to activate Mobility assistance plans that would help PWD to a nearby safer environment including the designated shelter. The evacuation assistance plan should also enumerate a list of accompanying necessities – i.e. Products and Technology – such as medicines, equipment for personal daily living and mobility, and products and technology for communication. Due to the fact that the PWD were not able to rely on regular service and care personnel for the mobility assistance, it is also important to build an alternative mobility assistance team in the neighborhood community. Second, sheltering assistance plans need to be activated in the 10 to 100 hour time phase. Such Self-Care needs as washing oneself, caring for body parts, toileting, dressing, eating, drinking and looking after one's self are critical in this period and therefore the matching reasonable accommodations need to be arranged at every designated shelter. Third, 100 to 1,000 hour phase is characterized by gradual re-entry into post-disaster normalcy when PWD face the tasks associated with Domestic Life such as acquisition of necessities, household tasks, and caring for household objects. It is expected that a large number of disaster volunteers could be coordinated in order to respond to these needs. Third, specific needs that require expert and professional assistance also tend to arise during the same phase for utilizing Services, Systems and Policies in utilities, services for communication, transportation, civil protection, legal and administrative applications, social security, general social support, and health. Professional volunteers and other outside experts/professionals could be mobilized to respond to these needs. Fourth, the phase over 1,000 hours is characterized by such General Tasks and Demands as handling the continuing stress and other demands in post-disaster recovery time. Traumatic stress prevention programs that focus on PWD may need to be prepared. Last, it is essential that the above indicated solutions need to be pre-planned before the next disaster hit the society.

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Notes

- 1 Total Quality Management methods were developed in order to improve product quality from the perspective of factory assembly line workers (Nayatani, Eiga, Futami, & Miyagawa, 1994). The purpose of Total Quality Management workshop is to sort out verbal data, to stimulate creativity, to put complex problems into solvable form, and to ensure that nothing is left out when planning. Sendai PWD workshop utilized affinity diagram, one of the seven TQM tools that were developed by Nayatani and his associates. The participants from divergent impairment categories formed small group (six to seven members) Quality Control circles at the workshop. Each participant independently produced verbal data on experienced life difficulties on post-it cards on a one-experience-on-one-card basis. After all verbal datum were collected, cards were grouped based on the affinity, i.e., the cards with similar statements were empirically clustered into a more summative grouping. In Sendai workshop, each summative grouping was then classified according to ICF and disaster time phase.
- 2 For more detailed definitions of all ICF definitions, please refer to the ICF illustration library: http://www.icfillustration.com/icfil_eng/top.html

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