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Research Article

An analysis to improve regional information accessibility to promote the “health for a care-focused mature society”

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Abstract

The purpose of this research is to identify issues arising with developing infrastructure for improving information accessibility within a care-focused society. We organized a symposium, “Building bridges in support of communication,” and the discussion was analyzed. Issues were organized into a “need to disseminate public awareness for the person with disabilities,” “need for surveys and information from the viewpoint of concerned parties,” and “promotion of an integrated support system.” It was thought that construction of "Disability Database," which was a disability registry using “clinical efficacy information,” would be able to contribute to improve the information accessibility for all, including people with disabilities.

Keywords: information accessibility, disability health and welfare policy, regional care-focused mature society, communication support, disability registry database, "definition of health for a care-focused mature society"

Introduction

“Information Accessibility” promotes an environment where people, regardless of the presence of a disability, can easily obtain and use information available to all. Augmentative and Alternative Communication (AAC) refers to communication methods used for supplementing or replacing speech or writing for those with communication and/or comprehension impairments [1-2]. Systematic AAC method classification for each type of disability is necessary for promoting an environment with sufficient information accessibility.

Our study group, “Research on How to Effectively Support People with Communication Disabilities obtain Equal Access to Information,” focused on a wide range of disabilities [3], including visual, hearing, and deaf-blindness disabilities, as well as developmental disorders [4], aphasia [5- 6], and amyotrophic lateral sclerosis (ALS) and other movement disorders [7], and intractable diseases and intellectual disabilities [8]. Each of these conditions is covered by the Comprehensive Disability Support Act and highlight key areas in need of communication support (Table 1).

The main objectives of this research were to identify issues arising during infrastructure development for improving information accessibility within a care-focused society.

Materials and Methods

Symposium: “building bridges in support of communication”

We conducted a symposium entitled, “Building bridges in support of communication,” during the course of the Comprehensive Research Project on Persons with Disabilities Policy (Figure 1) [9].

Setting up a participation venue

For publicizing the symposium, we set up a dedicated page for public symposium on the website of the National Institute of Public Health, and requested distribution of

Table 1. Outline of communication support needs by type of disability

Type of disability	Outline of communication support needs	Name of the survey etc.
Visual disabilities	Approximately 320,000 people [As of Dec. 1, 2011]	"Survey on difficulty of living etc."
Hearing disabilities	Approximately 320,000 people [As of Dec. 1, 2011]	"Survey on difficulty of living etc."
Deaf-blindness	Approximately 14,000 people [As of Oct. 31, 2012]	"A survey on the actual condition of deafblind people"
Aphasia	Approximately 200,000～500,000 people [As of Mar. 31, 2014]	"Aphasia Council survey"
Amyotrophic lateral sclerosis (ALS) [movement disorders plus dysarthria]	Approximately 9,000 people with ALS [As of Mar. 31, 2014]	"Hygienic administrative report example"
Other intractable diseases		
Intellectual disabilities	Approximately 550,000 people [As of Nov. 1, 2005]	"Basic research on intellectually disabled children"
Hattatsu shōgai (Developmental disorders)	About 6.5% of elementary and junior high school students) [As of May 1, 2013]	"MEXT Survey" (MEXT: The Ministry of Education, Culture, Sports, Science and Technology)
Higher brain dysfunction	Approximately 270,000 people [2001～2005 Survey]	"Higher brain dysfunction support model project"
Mental disorder	Approximately 320,000 people [As of Oct. 1, 2011]	"Patient research"

Note: The author reorganized and created this data based on meeting materials from the 69th Social Security Council Disability Subcommittee from the Ministry of Health, Labour and Welfare (2015/09/08 Document 2 -1 "Dispatch of persons who conduct sign language interpreters etc. Other ways of assistance for persons with disabilities that are communication obstacles include issues due to language functions, voice functions, and other obstacles").

posters and leaflets through 104 related facilities.

On the day, we set up a venue that allowed for participation, even if a communication difficulty was present. Abstract scribes (5 individuals) sat in the front row of the auditorium. ALS patients with wheelchairs and artificial respirators, together with two caregivers, could participate in a prepared area. A symposist, who was a medical professional with a hearing disorder, was also able to participate in the discussion. The symposist gave a lecture and participated in the discussion through the abstract scribes, sign language interpreter, etc.

Research related to effective support methods

This symposium dealt with research designed to produce effective support methods for information assurance among persons with communication difficulties. Through speeches and discussions, issues related to improve regional information accessibility were identified. To analyze, an iterative mode approach [10] in qualitative research was used.

Results

Of the 60 applicants who participated in advance, breakdown of 53 participants on the day was 35.8% for persons with disabilities and 24.5% for administrative officials [11].

These issues were organized into the following four themes:

1. "The need for a revolution of awareness, specifically toward 'the main concerned parties' and the greater public, including healthcare workers and providers of health and welfare nursing services who provide various disability support care that is available to regional residents"

Table 2. Program: Public Symposium "Building Bridges in Support of Communication: In Search of Ways to Support People with Various Communication Disabilities" . Thursday, December 1, 2016 at Seiryo Kaikan Hall, Tokyo

12:30 p.m.	Opening	
12:30–12:35 p.m.	Opening Remarks (Keynote Remarks)	Dr. Tomoko Tachibana Chief Senior Researcher, Center for Public Health Informatics, National Institute of Public Health
12:35–1:05 p.m.	Lecture 1	"Subsequent Health Conditions of Patients Who Were Transported Out of an Area Affected by the Great East Japan Earthquake" Dr. Takashi Imai Director, ALS Care Center, Sendai Tokushukai Hospital, Tokushukai Group
1:05–1:35 p.m.	Lecture 2	"Equal Access to Information and Communication Support for People with Intellectual Disabilities" Dr. Ayako Uchinami Associate Professor, Department of Child Science, Shukutoku University Junior College
1:35–2:05 p.m.	Lecture 3	"Developmental Disabilities and Communication Support" Dr. Akira Otsuka Professor, Department of Social Services, Faculty of Human Sciences, Sophia University
2:05–2:20 p.m.	Recess	
2:20–2:50 p.m.	Lecture 4	"Hearing Disabilities and Communication Support" Ms. Kumi Hayase Pharmacist, Showa University Hospital Pharmacy
2:50–3:20 p.m.	Lecture 5	"Communication Support for People with Severe Physical Disabilities such as ALS and Muscular Dystrophy: From the *Kuchimoji* Method to Eye-Gaze Communication Boards, Mechanical Switches, and Cybernetic Switches" Dr. Takashi Nakajima, Deputy Director, National Hospital Organization Niigata National Hospital
3:20–3:55 p.m.	Panel Discussion	Cochairs: Dr. Tomoko Tachibana, Chief Senior Researcher, Center for Public Health Informatics, National Institute of Public Health Dr. Hiroshi Mizushima, Chief Senior Researcher, Center for Public Health Informatics, National Institute of Public Health
3:55–4:00 p.m.	Closing Remarks	Dr. Tomoko Tachibana Chief Senior Researcher, Center for Public Health Informatics, National Institute of Public Health Dr. Hiroshi Mizushima, Chief Senior Researcher, Center for Public Health Informatics, National Institute of Public Health
4:00 p.m.	Closing	

2. "A need for surveys and information from the viewpoints of concerned parties"
3. "The promotion of sharing pioneering approaches among local government authorities through the construction of information sites"
4. "The promotion of constructing an integrated support system based on reasonable, efficient, and effective 'equipment,' 'people,' and 'software.'"

Discussion

Communication is important for enabling individuals to select "how, where, and with whom to live, as well as a guide for a successful and desirable livelihood." To promote disability health and welfare policies, we have conducted research aimed at re-evaluating current initiatives from the perspective of trauma prognoses in recent years [12 -16]. Considering results of the present analysis and recent policy trends involving regional healthcare, medical treatment, welfare, and nursing for persons with disabilities, evidence-based policies should be promoted for improving information accessibility. To achieve this goal, this article proposes the construction of a disability

registry database from the perspective of "clinical information efficacy [17-18]," which focuses on patient information related to diagnosis, treatment procedures, treatment efficacy, etc. among individuals examined and/or treated at all medical institutions in Japan.

In Japan where population declines and labor force reduction due to the declining birthrate and aging population progress simultaneously, drastic reforms in healthcare are required. "Healthcare 2035" [19] has been proposed to further develop healthcare and lead the world as a maturing nation. We have been introducing the following two policy recommendations to contribute to the new vision,

1. "Disability Registry" construction as a prognosis/outcome indicator in medical database, and
2. "Definition of Health for a Care-focused Mature Society" : in a care-focused mature society such as Japan, the notion that "despite 'social, physical, and mental challenges' such as the disabilities acquired from trauma or disease, quality of life can be maintained and that one 'is able to' self-manage and aim for "self-actualization" should be added to the future "definition of health."[15-16]

It was thought that construction of the "Disability Database" will contribute to realize the health promotion for the "Health for a Care-focused Mature Society" from the viewpoint of improving the information accessibility for all, that is, including "people with disabilities."

Conclusion

1. Issues related to the improvement of regional information accessibility were identified as followings: "need for a revolution of awareness, specitically toward 'the main concerned parties' and the greater public," "need to disseminate public awareness for the person with disabilities," "need for surveys and information from the viewpoint of concerned parties," and "promotion of an integrated support system."
2. It was thought that construction of the "Disability Database" will contribute to realize the health promotion for the "Health for a Care-focused Mature Society" from the viewpoint of improving the information accessibility for all, that is, including "people with disabilities."

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Conflicts of Interest

There are no conflicts of interest to declare.

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