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RESEARCH ON UTILIZATION OF NATIONAL EMPLOYMENT WELFARE SERVICE BY PERSONS WITH INTRACTABLE DISEASES IN JAPAN

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Abstract

With the revision of the Services and Supports for Persons with Disabilities Act in 2013 to provide welfare service to patients with Intractable Diseases (IDs) and the enactment of a new act for these patients in 2015, employment support (ES) service for them has become an important issue in Japan because of the chronicity of many of the diseases. The objective of this research is to examine utilization of the ES welfare services, and to identify care expected from ES service providers and their current efforts. A questionnaire was mailed to every registered provider in Japan (12,483 locations). Among 6,053 respondents, 16 percent reported patients with IDs using their services, and that among them, 74 percent had a certificate of person of disabilities, which is not required under the current Act. As for the reasons for reporting non-utilization, the percentage of "absence of inquiry" was 77 percent, while that of "needed medical care," "insufficient staff/facilities" and "lack of appropriate work" were all less than 3 percent. The result shows that dissemination of the ES service is still insufficient, and patients with IDs, their families, support providers and medical professionals need to be familiarized with the service in details.

Keywords

Intractable Diseases, Employment Support

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1. Introduction

Many of intractable diseases (IDs) have become chronic in nature in recent years because of a range of technological advances in medicine, which has made it possible for patients with these diseases to lead relatively active social life. As a result, employment support service for them has become an important issue in Japan, and in order to address this issue, IDs have been defined as a disease, cause of which has not yet been detected, for which there is no established therapy and which is chronic and poses not only financial problems, but also a heavy burden on the patients' family including potential psychological burdens ("Definition of Nanbyo,"n.d.), and 130 specific diseases (see Table 1) have been designated as IDs. Having given the status of persons with disabilities to patients with IDs by the revision of the Services and Supports for Persons with Disabilities Act (SSPDA) in 2013 ("Act for Establishment," 2013) and enacted a new act for these patients in 2015("Healthcare Act,"2014), their utilization of National

Employment Welfare Service (NEWS) is expected to increase hereafter. Few researches on the utilization of NEWS in this area, however, have been conducted in the past. Support needs of patients with IDs and their families vary because long-term treatments are needed for many of the diseases, and patients' mental and physical functions do not remain fixed and rather undergo drastic changes. Although a comprehensive support system to ensure their life-long treatments and to support their social life has not been established yet, it is an urgent issue to propose and promote measures required to realize an inclusive society where they are able to lead a life with dignity in a community through social participation in the form of employment including one under an employment support (ES) scheme of social welfare. The objective of this research is to examine utilization of NEWS by these patients, and to identify care expected from ES service providers and their current efforts.

Table 1: *Representative Designated 130 Intractable Diseases by Classifications*

Classifications	Representative Diseases
Blood disease:	Idiopathic thrombocytopenic purpura Myelofibrosis, etc.
Immunological disease:	Systemic lupus erythematosus Aortitis syndrome, etc.
Endocrine disease:	Syndrome of abnormal secretion of prolactin Addison's disease, etc.
Metabolic disease:	Amyloidosis Primary hyperlipidemia, etc.
Neuromuscular disease:	Spinocerebellar degeneration Moyamoya disease, etc.
Visual disease:	Retinitis pigmentosa Optic neuropathy, etc.
Auditory/ disequilibrium disease:	Idiopathic bilateral sensorineural hearing loss Ménière's disease, etc.
Circulatory disease:	Restrictive cardiomyopathy Idiopathic cardiomyopathy, etc.

Respiratory disease:	Early-onset chronic obstructive pulmonary disease Alveolar hypoventilation syndrome, etc.
Digestive disease:	Crohn’s disease Ulcerative colitis, etc.
Skin and connective disease:	Neurofibromatosis Scleroderma, etc.
Bone and joint disease:	Ossification of posterior longitudinal ligament Idiopathic osteonecrosis of the femoral head, etc.
Kidney/urology disease:	Polycystickidney IgA nephropathy, etc.
Others:	SMON

2. Methods

There are three types of NEWS providers in Japan. One type is specialized in transition support for employment (TSE), and there are 2,655 of them. Another type, called Type A, is specialized in continued employment support (CES) for people who are able to work more than 19 days under a labor contract based on the Labor Contract Act (“Difference Between,”2015, February 12), and there are 1,725 of them. The last type, called Type B, is specialized in CES for those who are unable to work more than 19 days under the labor contract (“Difference Between,2015,” February 12), and there are 8,103 of them. While the use of a TSE provider is limited for two years since the main objective of the training provided there is to get employment, there is no time limitation for the use of a Type A or Type B provider. An exhaustive survey of all registered NEWS providers in Japan was conducted, and a self-reporting questionnaire, which was customized according to their specialties, was mailed to 12,483 locations. All the response data were collected at National Rehabilitation Center for Persons with Disabilities (NRCPD) to be aggregated. This research was conducted according to the ethical guidelines for epidemiology research developed and implemented on April 1st, 2002 by Health, Labour and Welfare Ministry (HLWM) and Ministry of Education, Culture, Sports, Science and Technology (MEXT) of Japan.

3. Results

The overall response rate to the questionnaire was approximately 50 percent, and of 6,053 responses, 960 ES service providers (148 TSE service providers, 185 Type A service providers and 625 Type B service providers), which account for 16 percent, reported the utilization by patients with IDs as of the response date. Of those users, 74 percent have been issued the disability certificate (physical disability certificate, 44 percent; intellectual disability certificate (medical rehabilitation handbook), 21 percent and mental disability certificate, 9%). 94 IDs were reported in the responses, and the diseases that were reported most frequently were spinocerebellar degeneration (11.3 percent), moyamoya disease (8.3 percent), retinitis pigmentosa (7.8 percent), rheumatoid arthritis (5.4 percent) and Parkinson disease (4.9 percent). 37 IDs including Creutzfeldt-Jakob disease (CJD), sub-acute sclera singpanence halite’s (SSPE), Addison's disease, autoimmune hepatitis (AIH) and Budd-Chiari syndrome were not reported at all.

As for the reasons for reporting non-utilization, the percentage of “absence of inquiry” was as high as 77 percent, while that of “needed medical care,” “insufficient staff/facilities” and “lack of appropriate work” were as low as 1.5 percent, 2.2 percent and 1.0 percent, respectively.

The average days of the use of the services was 17.5 days per month, and the average monthly wage at the Type A CES and Type B CES service providers were JPY 66,212 (approximately USD 538) and JPY 14,851 (approximately USD 121), respectively. As for the type of work they are assigned, light labor is most common, accounting for 55.4 percent, followed by computer operation and cleaning tasks.

68 percent of the respondents reported having some kinds of special care for the patients with IDs. While special care regarding assigned task itself was most frequently reported, special cares regarding work hours, work place, break time, doctor’s visit, work procedure and communication method were also reported at comparable level (see Figure 1).

4. Discussion

The questionnaire revealed that patients with IDs uses the services of approximately 16 percent of NEWS as of December of 2013, which is the first year of the revised SSPDA. Considering the result that majority of the reason for reporting non-utilization was “absence of inquiry,” the welfare service available to the patients with IDs might not be sufficiently publicized currently, and this is an issue that needs to be addressed. Information that NEWS service providers seek when they consider an application by a patient with IDs were as follows: disease specific issues that a provider should be aware of, physical issues that a user him/herself should be aware of, measures to be taken in case of an emergency, medication a patient is taking and prognosis. Since use of their service under medical treatment is often expected, providers tend to seek information on issues not only they should be aware of as a service provider, but also issues the patient him/herself should be aware of regarding self-management. These kinds of information need to be provided by medical facilities. However, medical facilities often do not know the specific work the patient with IDs does at a given facility, and therefore, in order to provide needed medical information, a certain specific format needs to be prepared.

According to data counted for each disease, 94 out of 131 IDs were reported to have patients using the NEWS service providers. As for the possible reasons for 37 IDs that do not have patients using the service, small number of patients with these IDs and their progression rate too fast to make it chronic in nature can be suggested. It may be also important to publicize the availability of the NEWS service in the medical facilities specialized in these diseases as many of them are disorders of endocrine system, metabolic abnormality and digestive system disorders except for the cases of ulcerative colitis and Crohn disease.

Approximately 90 percent of patients with IDs who use the NEWS services have one of official disability certificates, and the percentage of patients without the disability certificate was only 6.6 percent. According to the SSPDA of 2013, patients with IDs are eligible for the NEWS service even he or she does not have the disability certificate, provided that the patient has a doctor’s certificate for the disease. Insufficient dissemination of this eligibility criterion could account for the small percentage of patients with IDs without the disability certificate using the NEWS service.

5. Conclusions

The revision of the SSPDA in 2013 should pave the way for the patients with IDs to utilize the welfare services that have been traditionally limited to persons with disabilities. As of 2013, approximately 16 percent of the NEWS providers have patients with IDs included in their users, and in the past five years, 20 percent of them had those patients included one time or another. The high percentage, nearly 80 percent, of respondents who reported "absent of inquiry" as the reason for not having patients with IDs in their users might be the result of insufficient publication of the revision of the act. Also, the high percentage, as much as 74 percent, of the NEWS users having one of three types of disability certificates might be the indication of inadequate dissemination of the fact that a doctor's certificate is sufficient to use their services. Further effort to familiarize all the parties concerned with the services and their requirements in detail is necessary to help promote the dissemination of the measures for patients with IDs.

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