

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 detail.

Perceptions and Support Needs of Individuals with Intractable Diseases Regarding a Range of Work-Related Issues

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Abstract

A number of persons with intractable diseases (IDs) experience work-related problems that could lead to job loss. The objective of this study is to obtain perceptions and support needs of individuals with IDs regarding a range of work-related issues. People aged 15 to 64 years old with one of 130 designated chronic diseases were invited to participate in the study. Data were collected through a self-report questionnaire. 3,000 questionnaires were mailed with assistance of patient organizations. The questions included demographic variables, family concerns, employment/supported employment, work accommodations, and other aspects of their lives. Among 889 respondents, 47 percent reported being unemployed due to fatigue and/or long-term treatment. Nearly half of the unemployed respondents reported that they had been unable to work despite their willingness to do so. Their common accommodation requests included flexible work hours, working at home and job/workplace modification. Only 30 percent knew of job training programs and supported work available for persons with disabilities. The results of the study are relevant for employees, employers and occupational health/human resource professionals. In order to promote sustainable work for persons with IDs, the issue of reasonable accommodations for them needs to be addressed in future research.

Key words: Intractable, Chronic Disease, Employment, Supported, Social Welfare