



Research on Problems in Employment Management and Support with regards to Employment of Persons with Intractable Diseases (Research Report No. 103) Summary

[Keywords]

Safety considerations, reasonable accommodations, cooperation of medical institutions and work places, International Classification of Functioning, Disability and Health (ICF), chronic disease

[Key points]

As a result of efforts to create countermeasures for intractable diseases in the past 40 years, many persons with intractable diseases are able to work if arrangement for hospital visit and reduced workload options such as deskwork are provided. This study demonstrated such situations, problems and proper employment management at work, local medical care, and support for employment using the empirical data. It also provides data for various diseases to offer appropriate employment management and support, that combine disease management and safety considerations with promotional work support.

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1. Authors (in Writing Order)

Yuichiro Haruna (Researcher, Research Group on Social Support, NIVR)

Kikuko Toumei (Research Cooperator, Research Group on Social Support, NIVR)

Setsuko Kohzai (Research Cooperator, Research Group on Social Support, NIVR)

2. Period of Research

FY2009 to FY2010

3. Composition of the research report

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4. Background and Purpose of Research

The following difficult challenges were residual for the employment of persons with intractable diseases

- Support for those who are not eligible for Disability Certificate but need employment support
- Resolution of dilemma between safety consideration at work and promotional employment support for persons with diseases
- Local coordination for medical care and work etc. that there have not been sufficiently in this study, in order to obtain empirical data for discussion of employment management and support, those problems were structured based on the conceptual framework of the International Classification of Functioning, Disability and Health (ICF).

This study focused on vocational problems in persons with intractable diseases, and clarifies an effective employment management at work places and a proper employment support in the community based on the empirical data. The study also clarified characteristics of vocational difficulties associated with intractable diseases which were observed in various aspects of working-life before and after getting a job, including comparison with those in persons with physical/ intellectual/ mental disabilities.

5. Method

(1) Data for analysis

This study analyzed the data obtained from: the survey conducted in 2005 exclusively over persons with intractable diseases and the survey conducted in 2009 over persons with physical/ intellectual/ mental and various other disabilities (including intractable diseases). In these two surveys, responses were collected by mail directly from the persons with intractable diseases and other disabilities in cooperation with the patients' associations and groups of people with disabilities. Many questions were commonly used in the two surveys so that the data were pooled for analysis as appropriate. This arrangement enabled: analysis with maximum 5,915 patients with 25 diseases and 8 diseases by with and without Disability Certificates; and comparison with the maximum of 36 kinds of various physical/ intellectual/ mental disabilities (referred to as "3 disabilities etc." hereinafter).

(2) Surveyed items and analysis

A cross tabulation was performed by presence/absence of problems in various vocational domains (activities and participation) and by presence/absence of various efforts at work and in the community (environmental factors). A statistically significant tendency where "presence of specific efforts results in fewer problems while absence of such efforts results in more problems" identified the effective efforts. The analytical result also revealed that difference of incidence of vocational problems with/without effective efforts. The result also clarified vocational problems which are seen in many users of local support organizations. The same analysis was performed on data from persons with various physical/ intellectual/ mental disabilities to compare the situation with that of persons with intractable diseases.

6. Summarized Results of the Study

(1) Overview of employment of persons with intractable diseases (See Table 1)

Persons with intractable diseases without Disability Certificates have some vocational problems and support needs at work places and in the community. However, the number of problems in these persons was equal or lower than the fewest number of problems among the persons with 3 disabilities etc who have the least need of support. Those who have jobs were mostly engaged in deskwork (clerical job, specialists, technological job), and employed as full time or regular workers. On the other hand, persons with intractable diseases with Disability Certificates had the similar extent of vocational problems, support needs, necessity of special arrangements and offered arrangements at workplaces and in the community to those of persons with moderate physical disabilities. However, many of the persons with intractable diseases without Disability Certificates found it difficult to effectively utilize various support systems and services. They also had more difficulties when explaining their diseases and requesting necessary accommodations to workplaces in comparison with those with Certificates or those with 3 disabilities, etc. They actually received less accommodations offered at workplaces when they needed it.

Table 1 Occupations in which persons with intractable diseases engaged

		Administrative and managerial	Specialist & technical	Clerical workers	Sales	Service	Security	Agriculture Forestry, fishery	Production	Transport Machine operator	Construction, mining	Delivery, cleaning, packaging	unclassifiable
Behcet's disease	With Certificate	11.1%	44.4%	22.2%	11.1%	0.0%	0.0%	0.0%	5.6%	0.0%	0.0%	0.0%	5.6%
	Without Certificate	7.7%	28.8%	15.4%	15.4%	11.5%	0.0%	5.8%	5.8%	3.8%	1.9%	3.8%	0.0%
Multiple sclerosis	With Certificate	8.3%	27.8%	36.1%	8.3%	13.9%	0.0%	0.0%	2.8%	0.0%	0.0%	2.8%	0.0%
	Without Certificate	0.0%	28.8%	25.0%	15.4%	13.5%	0.0%	0.0%	7.7%	0.0%	0.0%	5.8%	3.8%
Myasthenia gravis	With Certificate	4.8%	28.6%	28.6%	4.8%	14.3%	0.0%	0.0%	19.0%	0.0%	0.0%	0.0%	0.0%
	Without Certificate	2.7%	27.3%	32.7%	5.5%	15.5%	0.0%	1.8%	<u>4.5%</u>	0.0%	2.7%	3.6%	3.6%
Systemic lupus erythematosus	With Certificate	2.6%	28.9%	47.4%	2.6%	5.3%	0.0%	0.0%	2.6%	0.0%	2.6%	5.3%	2.6%
	Without Certificate	0.0%	28.4% ⁺⁺	34.0% ⁻	<u>6.1%</u> ⁻⁻⁻	13.2%	2.0% ⁺	0.0%	7.1%	1.0%	0.0%	6.1%	2.0%
Scleroderma/ polymyositis/ dermatomyositis	With Certificate	0.0%	44.4%	33.3%	0.0%	0.0%	0.0%	0.0%	11.1%	0.0%	0.0%	11.1%	0.0%
	Without Certificate	3.7%	30.9% ⁺	34.6%	8.6%	8.6%	0.0%	<u>0.0%</u>	<u>4.9%</u>	0.0%	1.2%	4.9% ⁻	2.5%
Ulcerative colitis	With Certificate	0.0%	30.0%	50.0%	0.0%	10.0%	10.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
	Without Certificate	4.8% ⁺	27.1%	32.4%	<u>6.9%</u>	7.4%	0.5%	1.1%	<u>8.5%</u>	2.1%	1.1%	3.7%	4.3%
Crohn's disease	With Certificate	2.6%	24.7%	36.4%	7.8%	3.9% ⁻	0.0%	0.0%	10.4%	1.3%	1.3%	11.7% ⁺	0.0% ⁻
	Without Certificate	3.6%	26.7%	24.8%	9.7% ⁻	10.9%	1.2%	0.6%	11.5%	3.0%	1.8%	3.6%	2.4%
Moyamoya disease	With Certificate	2.1%	8.3%	22.9%	10.4%	10.4%	0.0%	2.1%	14.6%	0.0%	0.0%	29.2%	0.0%
	Without Certificate	2.5%	24.0% ⁺	29.8%	8.3%	14.0%	1.7%	0.8%	<u>5.8%</u>	0.0%	0.8%	9.1%	3.3%
Retinitis pigmentosa		0.0% ⁻	40.0%	37.1%	2.9% ⁻	5.7%	0.0%	2.9%	2.9%	0.0%	2.9%	0.0%	5.7%
Parkinson's disease		12.9%	29.0%	29.0% ⁺⁺	0.0% ⁻	6.5%	0.0%	0.0%	6.5%	0.0%	6.5%	9.7%	0.0%
Spinocerebellar degeneration		0.0%	24.0%	24.0%	4.0%	20.0% ⁺	0.0%	0.0%	12.0%	8.0%	0.0%	8.0%	0.0%
Ossification of posterior longitudinal ligament (OPLL)		9.4%	31.3%	37.5% ⁺	6.3%	6.3%	0.0%	0.0%	6.3%	0.0%	0.0%	0.0% ⁻	3.1%
Mixed connective-tissue disease		2.1%	25.5%	29.8%	12.8%	14.9%	0.0%	0.0%	6.4%	0.0%	0.0%	6.4%	2.1%
Aortitis syndrome		0.0%	15.8%	57.9%	10.5%	5.3%	0.0%	0.0%	5.3%	0.0%	0.0%	5.3%	0.0%
Chronic inflammatory demyelinating neuropathy (CIDP)		3.4%	34.5%	37.9% ⁺	13.8%	6.9%	0.0%	0.0%	<u>0.0%</u>	0.0%	0.0%	0.0% ⁻	3.4%
Aplastic anemia		0.0%	26.3%	26.3%	8.8%	12.3%	0.0%	7.0%	12.3%	1.8%	1.8%	1.8%	1.8%
Sarcoidosis		10.0%	26.7%	20.0%	10.0%	6.7%	3.3%	0.0%	10.0%	0.0%	0.0%	6.7%	6.7%
Burger's disease		0.0%	13.3%	0.0% ⁻	13.3%	26.7%	13.3%	0.0%	13.3%	13.3%	6.7%	0.0%	0.0%
Neurofibromatosis type 1		0.0%	27.1% ⁺	15.3%	<u>0.0%</u>	16.9%	0.0%	1.7%	18.6%	1.7%	3.4%	13.6%	1.7%
Primary immunodeficiency syndrome		0.0%	50.0%	5.0%	5.0%	5.0%	0.0% ⁻	0.0%	5.0%	0.0%	5.0%	20.0%	5.0%
Insulin-dependent diabetes mellitus (IDDM)		1.6%	31.1% ⁺	29.5%	13.1%	14.8%	0.0%	1.6%	<u>1.6%</u>	0.0%	0.0%	4.9%	1.6%

(The distribution of individual diseases by gender/ age was compared with the occupational compositions by gender/ age in the labor force survey in 2009. ■: higher than in the labor force survey with p<0.01; ▒: higher with p<0.05; ▒: lower with p<0.05; ▒: lower with p<0.01.)

(In comparison of present job with previous job: ++: higher with p<0.01; +: higher with p<0.05; --: lower with p<0.05; -: lower with p<0.01.)

(2) Characteristics of work problems and effective efforts with intractable diseases

With the comprehensive analysis of both work problems and measures at workplace and local community, we demonstrated that persons with intractable diseases, in comparison with persons with 3 disabilities etc, faced more problems in stage of work preparation, finding jobs, and satisfaction and confidence in vocational life because effective local support was not sufficiently provided. On the other hand, work problems in workplace showed a huge difference with and without effective measures. In the workplaces where effective measures were provided, there were as small problems as in employees without disability in terms of communication, intellectual work and human relations. Problems and effective measures in workplace vary depending on the type of diseases. If the measure was not effective, problems arose in self care, regular report for work, and continuation of work at a level higher than those of persons with 3 disabilities etc.

Work problems differing depending on measures at work and in community:

A case of "Crohn's disease"

Work problems in Crohn's disease vary depending with/without effective measures as shown in Table 2 on the next page. It is necessary to indicate not just by single values but by a range of values depending on measures. Various work problems in Crohn's disease were summarized in the following figure based on the analysis in this study.

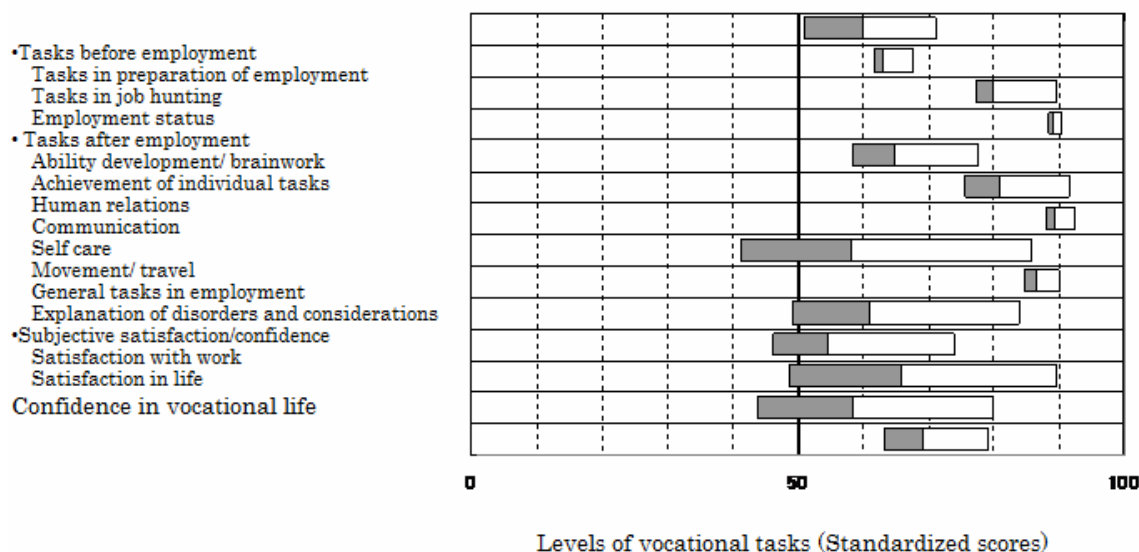


Figure Summary of work problems in Crohn's disease associated with effective measures

- The graph shows a profile of work problems which may differ according to with/without effective measures.
- The scale is a standard scale of problems relative comparison with various types of disabilities/ status of measures. The score 95 or higher is considered no problem (The same as the case of without disability); The score 0 is considered as the largest problem throughout the various types of disabilities without measures
- Work problems were averaged for 14 representative domains.
- The left end of the gray/white horizontal bars indicates the incidence of problem-free persons without effective measures shown in Table 2. The right end of the bar indicates those with all the measures in Table 2. The current executing rate of effective measures are between the two extreme, so that the current incidence of problem-free persons is indicated as the value on the border of gray and white bars.

The following were specifically identified as a series of effective measures that affect the work problems for persons with Crohn's disease.

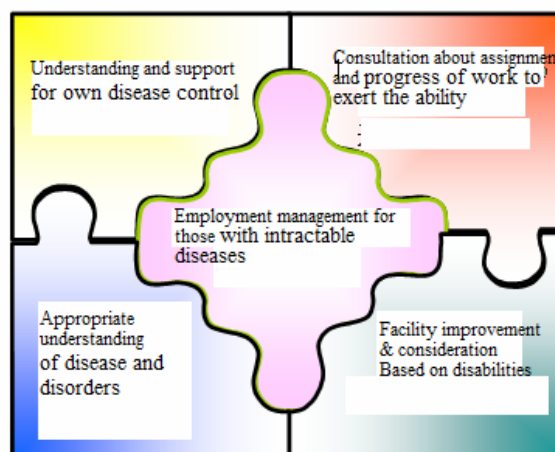
Table 2 Measures found effective in improvement of problems in various work stages in persons with Crohn's disease

Stage of work problems	Measures found effective in improvement of work problems
Problems before employment	Consultation on work with family, relatives, acquaintances, friends*; referral to work places; Consultation on work with persons or organizations* with the same disease
Status of employment	Consultation on employment with general staff at Public Employment Service Offices; referral to workplaces; Consultation on employment with doctors/ specialists*
Problems in workplace	Appropriate understanding of diseases/ disabilities from boss/coworkers; consideration for hospital visit; personnel policy that allows career advancement regardless of diseases/ disabilities; arrangement for rest at work; possession of Physical Disability Certificate; provision/preparation of facilities for rest and health management necessary at work
Problems of subjective satisfaction and confidence	Measures to proactively listen to opinions from the employee to improve work content; considerations for hospital visits; assignment to the work within capability; personal training for practical work (on-the-job training etc.); appropriate understanding of diseases/ disabilities from boss/coworkers; personnel policy that allows career advancement regardless of diseases/ disabilities

These results summarized necessary information for employment management and community support for persons with Crohn's disease. The results shown above indicated that work problems for persons with Crohn's disease in workplace were characterized by the issues of "self care" such as toilet and health management etc as well as "general issues in employment" such as continuation of work, promotion, and wages. The results indicate that these problems were significantly improved by effective measures. Other characteristic problems were: tasks of vocational preparation before employment; low satisfaction in work and life; many people who wanted to, but could not explain their diseases and request for accommodations. On the other hand, another vocational characteristic in persons with Crohn's disease was that many of them were as capable as those without disability in the domains of learning and brainwork, human relations, communication, movement/ travel etc.

The features of employment management commonly applicable for various intractable diseases were: cooperation from the workplace for hospital visit and self-management of disease; appropriate understanding of diseases in workplace; good communication in workplace to discuss how to maximize employer's ability; arrangement based on disability traits when the employees had Disability Certificates.

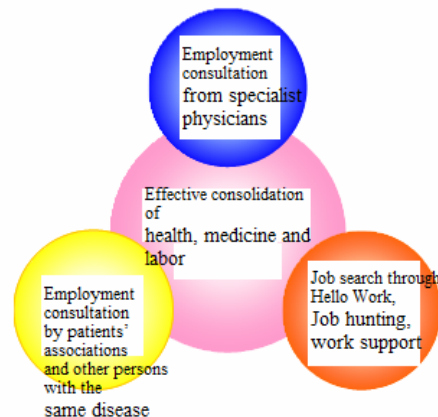
As for the employee without Disability Certificate, it was especially difficult to explain the disease and



necessary accommodations to the workplace. Therefore, effective measures included: consideration for hospital visit; appropriate understanding of diseases/ disabilities from boss/coworkers; good communication concerning work arrangements; elimination of unreasonable discrimination due to the disease itself in working conditions etc. Consultation with doctors about employment was also important in order to continue working.

(3)Challenges and possibilities of local support for employment of persons with intractable diseases

Not so many measures were determined to support employment of persons with intractable diseases. However, it was confirmed that Public Employment Service Offices, vocational rehabilitation centers for persons with disabilities, doctors, public health nurses, social workers, centers of consultation and support for intractable diseases, and patients' organizations offered effective consultation for employment. On the other hand, those who sought advice from the above



sources had many problems in continuation of work, regular report, work performance, health management, and rest etc. Based on these challenges observed after employment, it is important to effectively link medical support and labor support in order to reflect the result of employment consultation offered by doctors' and patients' association on job search and job accommodations. It is also important for various local related institutions to share common recognition of effective measures and offer appropriate referrals.

(4) Data book of intractable diseases in work situation

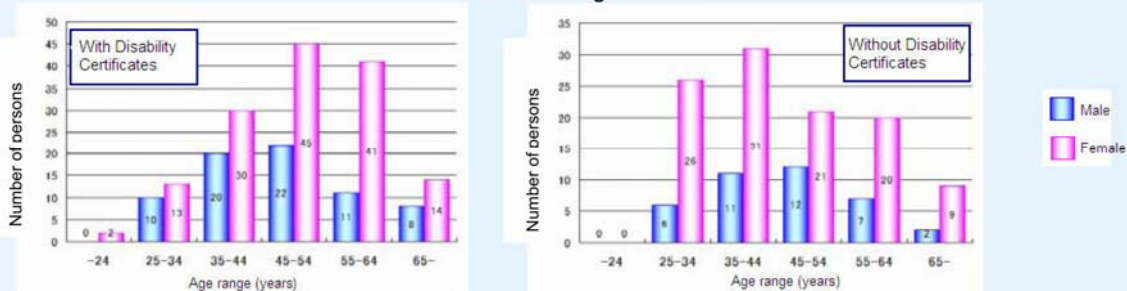
As intractable diseases are various and specific for each disease, detailed information should be provided in an understandable manner to be utilized for employment management. In a separate volume of this report, a "Data book of intractable diseases in work situation" was compiled. It summarizes characteristics of each disease; effective measures at work and their effect over work problems; specific job types and working conditions for each disease to be used for considering job types in which people with diseases could work.

2. Multiple Sclerosis (MS)

An inflammatory disease in which the white matter of the brain and spinal cord are damaged (demyelinating inflammatory disease), frequently occurring temporally and spatially.

Many of the persons with multiple sclerosis are able to work. However, repeated attacks accumulate neurologic damage and aggravate motor dysfunction. Workers with multiple sclerosis need understanding of the disease, and consideration and support such as introducing support equipment necessary for travel and work. In case of mild attacks (mild visual degradation, paresis of facial nerve, quadriplegia, etc.), workers, after having left the work place, can return to work in 4-5 days, or for a maximum of about 1 month, although there are differences among individuals. In case of moderate disorders (in a level where daily life is possible with some efforts and arrangement in spite of quadriplegia or limb ataxia), workers, after having left the work place, can return to work in 2 weeks, or for a maximum of about 2 months. In case of severe disorders (in a level where daily life is impossible without assistance from others), it is considered that workers, after having left the work place, can return to work in 2 weeks to 6 months.

Approximately 59.2% of the persons with MS possess Disability Certificates. Patients are relatively more women than men. Those who have not received the certificates are seen most in ages 20-40. Those who have the certificates are seen most in ages 40-60.



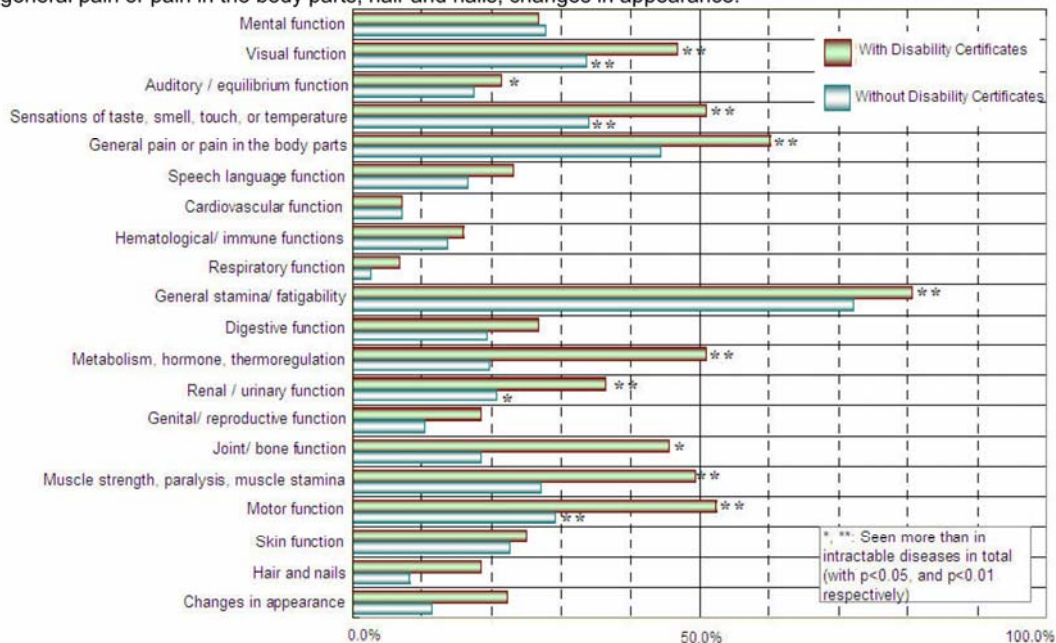
Relatively seen functional disorders

Major symptoms are: visual degradation; pain and numbness in extremities; leg-dragging walk; going to the toilet frequently; difficulty in urination. Repeated recurrence and remittance of symptoms shifts into chronic condition.

• Major symptoms in persons with Disability Certificates: loss of general stamina, fatigability; general pain, pain in the body parts; motor dysfunction; trouble in metabolism, hormone, thermoregulation etc.

• Major symptoms in persons without Disability Certificates: loss of general stamina, fatigability; general pain, pain in body parts etc.

• Functional disorders observed significantly more in those with Disability Certificates than in those without are: trouble in metabolism, hormone, and thermoregulation; renal function, voiding function; joint and bone function; muscular strength, paralysis, muscular stamina; visual degradation; sensations of taste, smell, touch, or temperature; general pain or pain in the body parts; hair and nails; changes in appearance.

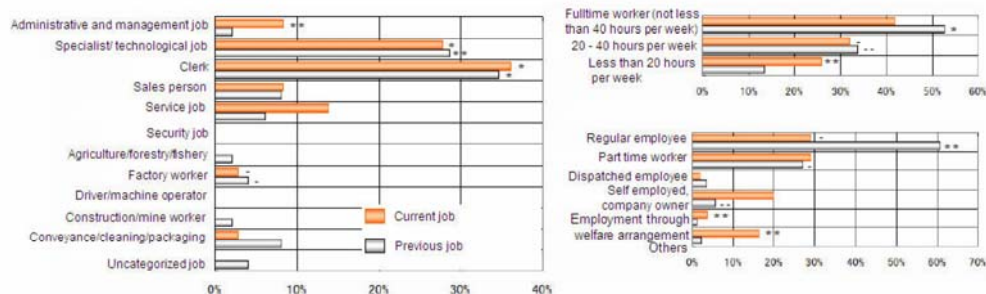


Persons with MS with Disability Certificates

[2] Occupations in which persons with MS are engaged

A total of 74.9% of persons with MS had working experience: 26.1% had a current job that generates income; 48.7% had previously had a job that generates income.

They were engaged more in administrative and management/ special/ technological/ clerical jobs; less in production line jobs in comparison with persons in the same gender and in the same age range. Employment in welfare arrangement was seen in relatively more cases than in other diseases; regular employment was relatively less; work less than 20 hours a week was relatively more in comparison with persons in the same gender and in the same age range.



(*, **: Particularly more cases are seen in comparison with persons in the same gender and in the same age range in 2009 Workforce Survey ($p < 0.05$, $p < 0.01$ respectively). -, -: Particularly fewer cases are seen.)

Examples of current jobs

[Specialists, technical jobs] (19.4%)

- Former researcher at a research institute. The aggravated disease required the use of a wheelchair. I became unable to commute and now am staying home. I visit the university once a week to continue my research (male in 50s).
- Non-regular employee engaged in machine design (male in 50s).
- Corporate LAN management (male in 30s).
- Nurse counseling as coordinator for hospital visit at the general reception of a hospital (former nurse) (female in 40s)
- Working at a hospital (male in 30s).
- Occupational therapist (female in 30s).
- Preparation of housing reform advice forms using Nursing-care insurance; coordination of housing reform; preparation of prescription of welfare devices (wheelchair etc.); advice on welfare devices (male in 40s).

[Various clerical jobs] (19.4%)

- Local government employee (documentation, printing, duplication) (male in 40s)
- Clerk (male in 30s)
- Bank clerk (female in 40s)
- Foreign pharmaceutical company (sales support in office) (female in 20s)
- Internship promoter in the association (male in 50s)
- Data entry into computer system (female in 40s)

[Personal computer operator] (13.9%)

- Data entry; tabulation (female in 40s)
- Data preparation/entry using terminal (female in 40s)
- General clerk; data entry on contract/cancellation into PC; contract management (male in 30s)
- System Office at a major supermarket (PC operation etc) (female in 40s)
- Data entry operator; data preparation for printing; audio typist (female in 30s)

[Service jobs] (13.9%)

- Simple daily assistance for the elderly or the sick (female in 40s)
- Home helper (female in 60s)
- Aid in eating or travel for persons with intellectual or physical disabilities (male in 30s)
- Laundry agent (female in 50s)
- Waitress during lunch hours at a coffee shop (female in 40s)

[Administrative jobs] (8.3%)

- Executive of a manufacturing company (male in 50s)
- Company executive (transferred from sales to general administration division) (male in 50s)
- Accounting; clerical work; serving tea for visitors (self employed) (female in 50s)

[Physicians, dentists, veterinarians, and pharmacists] (8.3%)

- Dentist (male in 40s)
- Pharmacist (marketing supervisor-general) (female in 50s)
- Pharmacist (at a dispensary that deals with few prescriptions) (female in 40s)

[Sales jobs] (5.6%)

- Owner of a photo studio (male in 40s)
- Investor (stock and FX) (male in 50s)

[Conveyance/cleaning/packaging] (2.8%)

- Packaging and shipping of semi conductors (male in 30s)