Empirical Research for Effective Cooperation of Supports for Independent Life and Work of People with Disabilities
(Research Report No. 100 and Supplements 1 and 2) Summary

[Keywords]

Person-centered viewpoint of people with disabilities, challenges for work, necessary arrangements, effective arrangements, ICF

[Key points]

What problems do people with disabilities or diseases face when they find and keep their jobs? What arrangements provided by local support organizations, workplaces, or the people are effective as solution of these problems? The NIVR conducted questionnaire surveys on the people and implemented model projects (to accumulate support cases in leading-edge support groups) for people with intractable diseases and developmental disabilities in order to measure and clarify the results of the arrangements quantitatively in statistical methods based on data obtained from the surveys.

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2. Period of Research

FY2008 to FY2010

3. Composition of the research report

Introduction

Framework of Research

Summary

Chapter 1　Purpose, Implementation Method, and Research Process

Chapter 2　Research Process of Questionnaire Survey

Chapter 3　Results of Questionnaire Survey

Chapter 4　Analysis of Results of Questionnaire Survey

Chapter 5　Results of Model Projects

Chapter 6　Considerations

Conclusion

The report consists of three volumes, i.e., Appendix 1 and Appendix 2 are prepared besides this main publication. The contents of the Appendixes are as follows:

(1) Appendix 1

This volume is a descriptive guide for the results of questionnaire surveys on selected types of disabilities based on the number of data in the rough classification of disabilities.

(2) Appendix 2

This volume shows the results of the analysis of the questionnaire surveys of residual types of disability and disease (provided that the number of data for each disability or disease is large enough for analysis).

To utilize the results of analysis of each type of disability or disease, you can search for the target item in the table of contents of Appendix 1 or 2.

In this research, effective arrangements were derived from the analysis based on responses from people with disabilities. In other words, effective means from the viewpoint of people themselves, which is the new feature of the research. From a viewpoint of workplaces, however, there may be unresolved problems or be free of problems. Moreover, effective arrangements vary with type of disability, type of work, and work environment. Those who refer to the effective arrangements should keep these in mind.

4. Background and Purpose of Research

Currently, arrangements to support people with disabilities to make job preparations are largely

expanding in each field of society, such as the fields of labor, welfare, medicine, and education. Moreover, not only for job preparations but also after finding jobs, it has been becoming important for life support and medical institutions to give proper support for the people with disabilities and their employees to adjust for and continue working.

Arrangements for the people with disabilities and their families for the people's independence and working life should be integrated continuously from their preparations, job finding, workplace adjustments, work continuation, and career progression; the realization of which is directly dependent of the environment arrangements of employers (workplaces) and those of local institutions, such as labor, welfare, and medical institutions. Therefore, various arrangements for their independent-living and working life should be integrated. For this purpose, the person-centered viewpoint of the people themselves as customers of the supports is important other than the framework of supporters, which tend to be divided within professional silos.

Therefore, we aimed to develop a common guidance for those concerning to independent-living and working supports, based on the integrated person-centered viewpoint. Effectiveness of current arrangements of various workplaces and local communities for independent-living and working-life were empirically evaluated based on the relationship between arrangements and problems experienced by the people.

5. Method
(1) Research Focus and Significance of Surveys and Model Projects
As described above, in order to promote working support for people with disabilities or diseases, it is necessary to clarify the problems they face in finding and maintaining jobs and effective arrangements in workplaces, by local support agencies, or by themselves.

We obtained data of ①conditions of their disabilities and diseases, ②status of functioning of their working life, and ③existence or absence of arrangements. Based on the data, we compared the incidence of problems with and without the arrangements. The range of the difference of the certain functioning with and without the certain arrangement is used as an objective index of the effectiveness of the arrangement.

Specifically, we conducted a questionnaire survey on the people with disabilities, implemented a model project for intractable diseases and developmental disabilities (to accumulate support cases in leading-edge support groups), statistically determined the effectiveness of various arrangements based on the data, and tried demonstrate the effective arrangements for the problems.

(2) Use of ICF Concepts
The concept of functioning varying with the arrangements made by workplaces and communities is based on the framework of the International Classification of Functioning, Disability, and Health (ICF) endorsed by the World Health Organization (WHO) in 2001. That is, functioning, such as activity and participation, depend on the interaction of individuals and the environment. The questionnaire designed using the framework and covering the domains of the Activities and Participation and Environmental Factors of the ICF.

(3) Establishment and Operation of Research Committee

In order to execute the research smoothly, we established a research committee consisting of representatives of groups of people with disabilities, employers, academics, administrative agencies concerned, and a researcher of the NIVR. We also established committees to promote model projects consisting of the representatives of cooperative organizations.

(4) Implementation of Fact-finding Survey with Questionnaires

In order to make a fact-finding survey, we listed up 69 problems and 134 arrangements for each aspect of work preparations, finding jobs, adjust for and continue work by referring to preceding researches that utilized the ICF in work settings.

With cooperation of the groups of people with disabilities, the NIVR sent questionnaires to 14,448 people with disabilities, and 4,546 people sent back their answers (collection rate: 31.5%).

(5) Implementation of Model Projects

We implemented model projects by assigning a coordinator for work support to each cooperative group (of four groups of people with intractable diseases and two groups of people with developmental disabilities). The coordinators implemented leading-edge supports and reported the cases monthly. We conducted a questionnaire survey similar to (4), and collected data on the problems and arrangements from the participants of the model projects. Also, we gained additional information about the promising supports from interviews of the coordinators.

We conducted longitudinal three surveys with the same content during the support period (at the beginning, intermediate point, and completion of the period) to grasp the changes of the condition. We made a statistical analysis of the results to determined the effectiveness of the promising supports and arrangements.

Through this model project, we collected data on support cases of 90 people with intractable diseases and 34 people with developmental disabilities.

6. Summarized Results of the Study
(1) Method for Estimation of the Effectiveness of the Arrangements for Problems based on the Survey, and its Examples
a. Method for Estimation of the Effectiveness of the Arrangements for Problems

First, we obtained the following items in all the combinations of 69 problems and 134 arrangements (69x134=9,246).

①Incidence of free of certain problem without certain arrangement

②Incidence of free of certain problem with certain arrangement

Then, the difference between them is referred to as "improvement range." The range was calculated for each combination. The arrangement with the most wide improvement ranges for certain problem for each type of disability was also determined.

We clarified combinations of those effective arrangements for problems for each type of disability and disease, and for stages of work preparation and after employment.

b. Examples of Analysis of Problems vs. Arrangements

As an example of the analysis, we described the following effective arrangements for problems on people with schizophrenia before and after finding jobs.

An explanation for the table is as follows:

The bar graph in the right column shows improvement in each problem made by the corresponding arrangements in the left column. The scale of the graphs shows the rate of people whose action assignments were improved. The gray part of each bar shows the improvement achieved by arrangements (with the improvement ratio shown in parentheses) and the white part shows the improvements on condition that the arrangements be made for all the applicable people (i.e., the arrangement ratio be 100%).

In addition, we selected effective arrangements influencing more number of the problems. Furthermore, we listed arrangements that have similar effects on problems and statistically significant correlations with the selected arrangements as well because these arrangements are considered to become effective when they are combined with other arrangements.
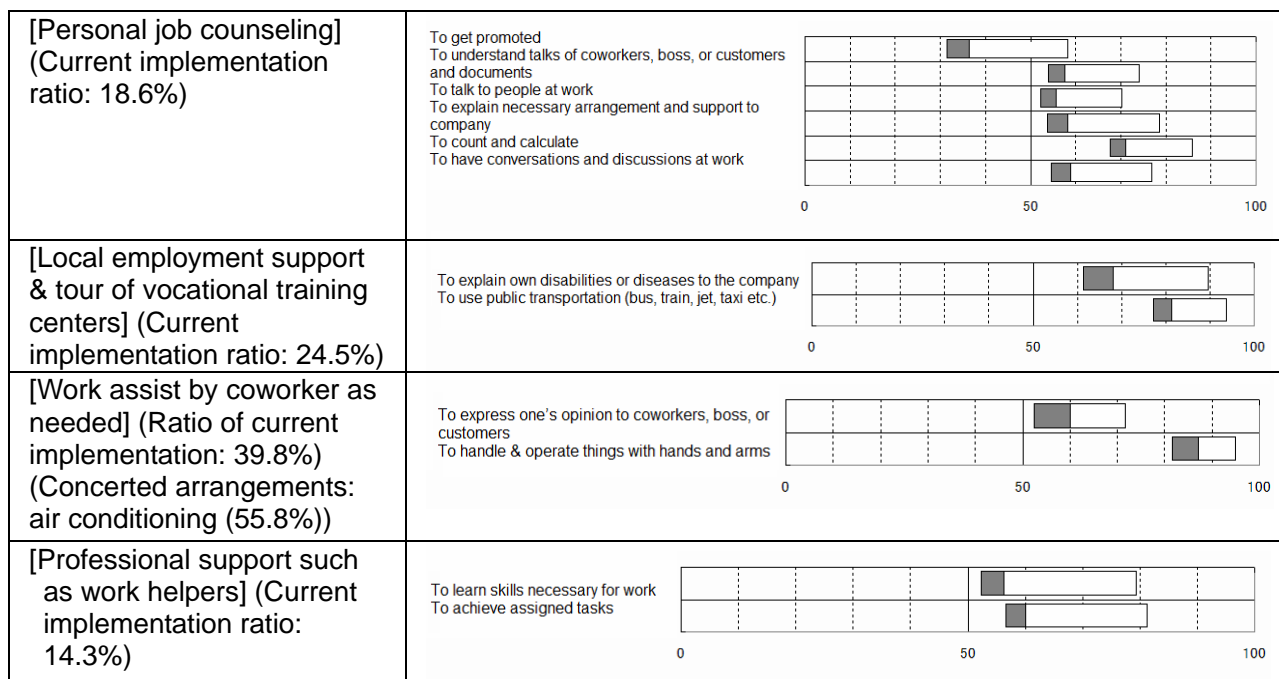
○ Schizophrenia

i. Effective arrangements for [problems prior to employment]

Effective arrangements	Work problems that will differ according to the presence or absence of the respective arrangement
[Training for life rhythm and work habit](Current implementation ratio: 49.5%) (Concerted arrangements: Practice of job interview & preparation of personal resume * (29.8%); support for license acquisition & vocational training by job types (24.5%))	To inform the employer of necessary arrangement at work; To effectively appeal to the employer; To collect information of desired company; To develop perspective in life accepting own disabilities; Tour of work place; vocational training; work experience; To contact a company; to apply for a job; To prepare resume & application form (scale 0–100)
[Support for license acquisition & Vocational training by job types] (Current implementation ratio: 24.5%) (Concerted arrangements: Referral to employers (22.1%); practice of job interview & preparation of resume (29.8%); personal job counseling (18.6%); trial employment (15.3%)	To effectively appeal to the employer; To inform the employer of necessary arrangement at work; To contact a company; to apply for a job; To acquire ability to get a desired job; Tour of work place; vocational training; work experience; To take a job interview; To prepare resume & application form; To inform other people of own will to get a job (scale 0–100)
[Evaluation of work ability/job aptitude test](Current implementation ratio: 24.2%) (Concerted arrangements: Referral to employers (22.1%); regular check & support for disabilities & diseases (17.8%); private	To collect information of desired company; To research on jobs where own ability is utilized; To develop perspective in life accepting own disabilities; To take a job interview (scale 0–100)

job counseling (18.6%); practice of job interview & preparation of resume (29.8%)	
[Trial employment] (Current implementation ratio: 15.3%) (Concerted arrangements: Referral to employers (22.1%); Job coach support, escort support to company (16.0%); support for license acquisition & vocational training by job types (18.6%))	To appropriately explain own disabilities or diseases to the company without causing misunderstanding To effectively appeal to the employer Tour of work place; vocational training; work experience To take a job interview To contact a company; to apply for a job To prepare resume & application form 0 50 100
[Support for daily life & life in community after starting work] (Current implementation ratio: 13.3%)	To research on jobs where own ability is utilized 0 50 100

ii. Effective arrangements over [problems after starting work]

Effective arrangements	Work problems that will differ according to presence or absence of the respective arrangement
[Consideration for hospital visit](Current implementation ratio: 58.4%) (Concerted arrangements: Appropriate understanding of bosses/ coworkers over diseases and disorders (33.0%))	To get promoted To appropriately deal with mental stress Stable and permanent position and content of work Decent payment Problem solving and judgment To deal with danger and other situations Communication at work To maintain smooth relation with the boss and coworkers To understand talks of coworkers, boss, or customers and documents To express one's opinion to coworkers, boss, or customers To have conversations and discussions at work To achieve assigned tasks at work To take a moderate rest to maintain efficiency at work To pay attention to one's work 0 50 100
[Appropriate understanding of bosses/ coworkers over diseases and disorders] (Current implementation ratio: 33.0%) (Concerted arrangements: Consideration for hospital visit (58.4%); Work assist by coworker as needed (39.8%); shorter working hours (44.6%))	To continue steady, constant work where position is secured To appropriately deal with mental stress To solve problems; to make decisions To appropriately deal with dangerous situations To have conversation & discussion at work To maintain smooth relationship with boss/coworkers To fulfill responsibility required at work To achieve assigned tasks To concentrate one's attention to work To take moderate rest and maintain efficiency To transport supplies To maintain own health; meals, rest & self treatment To go to toilet at work To move around various locations (including wheelchairs) 0 50 100
[Support to improve job skills for career advancements] (Current implementation ratio: 19.3%)	To have a fulltime work (about 8 hours) To earn a decent wage To read documents, books & instructions To come to work without delay, early leave or absence To maintain smooth relationship with boss/coworkers To work in a standing posture To take moderate rest and maintain efficiency To transport supplies 0 50 100

[Personal job counseling] (Current implementation ratio: 18.6%)	To get promoted To understand talks of coworkers, boss, or customers and documents To talk to people at work To explain necessary arrangement and support to company To count and calculate To have conversations and discussions at work
[Local employment support & tour of vocational training centers] (Current implementation ratio: 24.5%)	To explain own disabilities or diseases to the company To use public transportation (bus, train, jet, taxi etc.)
[Work assist by coworker as needed] (Ratio of current implementation: 39.8%) (Concerted arrangements: air conditioning (55.8%))	To express one's opinion to coworkers, boss, or customers To handle & operate things with hands and arms
[Professional support such as work helpers] (Current implementation ratio: 14.3%)	To learn skills necessary for work To achieve assigned tasks

The above graph shows typical arrangements effective to improve work problems for people with schizophrenia; training for life rhythm and work habit; support for qualifications and vocational training by job types; evaluation of work performance/ job aptitude test prior to employment. After employment, the following supports are considered to be effective for problem solving: arrangement for hospital visit; appropriate understanding in the boss/ coworkers of the disease/ disorders; support for learning occupational skills for career advancement.

(2) Model Project

The data of the questionnaire survey obtained from registered participants for the support cases were analyzed. Factor analysis was conducted on work problems and arrangements. As for wok problems, 13 significant factors were identified; as for arrangements in work places/ communities/ employees themselves, 19 were identified. The following are significant correlations recognized among the identified factors.

a. Intractable diseases (systemic lupus erythematosus, Crohn's disease, ulcerative colitis, Behcet's disease etc.)

(a) Problems prior to work and efforts associated with subjective satisfaction and confidence

• Problems in general job hunting activities decreased when trial employment system was utilized and when the employees themselves have optimistic viewpoints for the future.

• Employment situation was improved when individual confirmation of workplace and escort support to enterprises are available.

• Problems of job hunting and work status still persisted, although many of those who had those problems received explanations for job hunting such as utilization of job search machines.

• General satisfaction with work was associated with presence of recruitment seminars/ interview practice; close support of model project employment support coordinators; optimism; training/ guidance at work places.

- Confidence as professional in spite of the disease was associated with optimism; motivation to work; understanding and cooperation of the doctor.

(b) Efforts associated with general problems at work

- Explanation about the disease and needed accommodations to workplace and human relationships at workplaces were associated with close support of employment support coordinators; good communication with coworkers at work etc.
- Individual adjustment/ alteration of job assignment and content after the employer listens to the employee was associated with explanation of the disease and accommodation to workplace as well as securement of time for hospital visit.
- Treatment at work and stable employment were associated with trial employment.
- Commuting and regular work were associated with motivation to work.

b. Developmental disorders

(a) Problems prior to work and efforts associate with subjective satisfaction and confidence

- Many of those who were engaged in any type of work experienced escort support and practical training at work.
- Close support from the employment support coordinators in the model project was associated with strong confidence in participation to society while having disabilities.
- Strong confidence in participation to society while having disabilities was also associated with one's own sense of optimism.

(b) Efforts associated with general problems at work

- Getting a job at a workplace where understanding and appropriate work level were offered was associated with the existence of understanding coworkers and bosses; existence of various consideration/ natural support at work place; and utilization of quota system for employment of persons with disabilities / work-life support center.
- Many of those who had escort support or practical training at work were successful in getting a job suitable for themselves in competitive employment.
- Finding a job suitable for oneself was also associated with utilization of recruitment seminars and existence of understanding coworkers and bosses.