



# **Research on dissemination and improvement of the manual for employment management of persons with intractable diseases**

## **(Research Report No.141) Summary**

### [Keywords]

Reasonable accommodation, work-style reforms, support for balancing treatment and work life, recruitment, seating allocation at workplace, support for leave and reinstatement

### [Usage of this report]

We have developed an employment management manual to enable employers to implement employment management smoothly for persons with intractable diseases, by finding needs of employers who employ such persons, although, that is not subject to employment rate system for persons with disabilities, and by utilizing the storage of research of National Institute of Vocational Rehabilitation.

April 2018

Japan Organization for Employment of the Elderly, Persons with Disabilities and Job Seekers. (JEED)

National Institute of Vocational Rehabilitation

NATIONAL INSTITUTE OF VOCATIONAL REHABILITATION

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## 2. Survey Period

FY2016 to FY2017

## 3. Composition of the Research Report

Chapter 1: Background and Purpose of Research

Chapter 2: Making a prototype employment management manual

Chapter 3: Needs of employers for employment management manuals

Chapter 4: Actual cases of employment management for persons with intractable diseases (Visit and hearing surveys)

Chapter 5: Implication of employment management for the local supporting staff

Chapter 6: Promotion and improvement of the employment management manual for persons with intractable diseases

## 4. Background and Purpose of Research

Since 1996, National Institute of Vocational Rehabilitation (hereinafter called “NIVR”) has accumulated the research on situation of issues for employment of persons with intractable diseases and on direction of supports for employment, and has made it clear that, with continuous appropriate medical treatment, with works without excessive difficulty and with understanding and consideration from workplace, it is possible for many persons with intractable diseases to conduct works as an occupation. We have also proved that balancing medical treatment and work life of persons with intractable diseases depends on the existence of the effective implementation of employment management by employers, and that it is important to have a close coordination with the field of healthcare for achieving employment management balanced with medical treatment. In this regard, in order to have persons with intractable diseases continue their works without excessive difficulty, the employment management by employers and receiving supports from related fields are necessary and these two compose the two axes for the endeavor by persons with intractable diseases.

But up to now, measures to counter intractable diseases have been conducted mainly to persons with severe diseases in the field of healthcare and recognition and endeavor of employment supports have been limited. Moreover, many persons with intractable diseases who need employment support do not have Disability Certificate and are not subject to employment quota system for persons with disabilities. Such blind spot of social systems has been pointed out.

Recently, we have noticed a big progress in such support for persons with intractable diseases. By enforcement of “Act on Medical Care for Patients with Intractable Diseases(Intractable Diseases Act)” (2015) followed by “Basic Policy of General Implementation such as Medical Treatments for

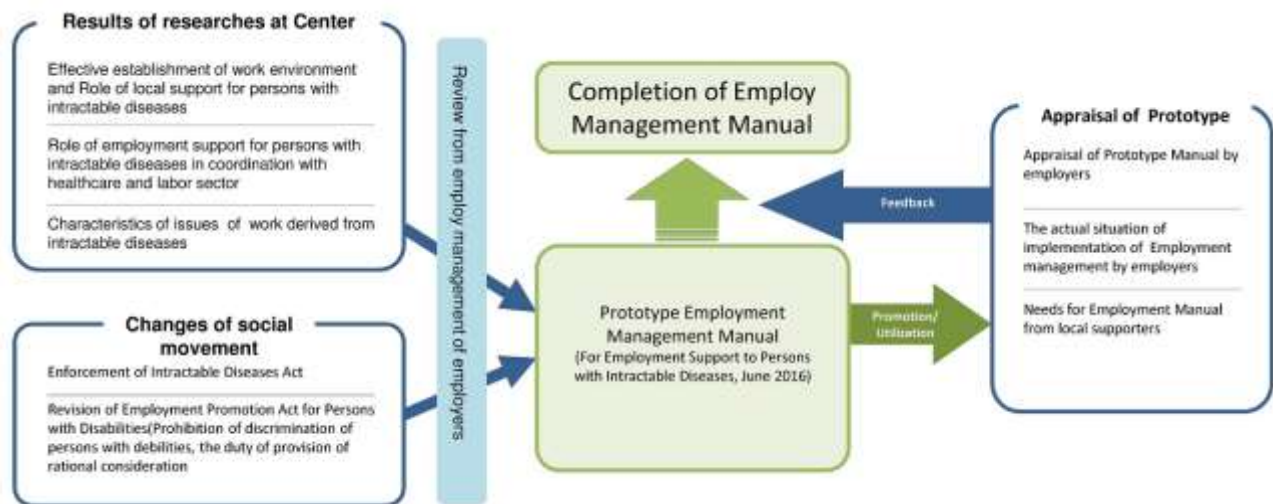
Persons with Intractable Diseases(Basic Policy)” (September, 2015), employment supports have been included in government measures to counter intractable diseases. Moreover, by enforcement of revised “Act on Promotions of Employment of Persons with Disabilities (Employment Promotion Act for Persons with Disabilities)” in FY2016, even though persons with intractable diseases are not subject to employment quota system for persons with disabilities, prohibition of discrimination against those persons and provision of rational consideration to them have become the duty for all employers. According to the above-mentioned changes, from the viewpoint of ways to implement employment support for persons with intractable diseases under the principle of inclusive society as basic policy of government’s measure to counter intractable diseases, it is regarded as a direction that the government should aim as practical issues, to establish work environment in which persons with intractable diseases can disclose their diseases and can balance their medical treatment and work life, to make manuals for such employment management and to establish support systems for employment supports and for job retention in each region.

NIVR has conventionally disseminated ways of effective employment supports for persons with intractable diseases to such persons themselves, to employers and to supporters in local healthcare and labor sectors through various manuals and tools. But now, in the face of big changes of social movement in employment support for persons with intractable diseases, the dissemination of employment support for persons with intractable diseases including employment management by employers, local supporting systems and development of professional human resources is regarded to be in a new stage.

In reference to the big changes of social environments for employment support to persons with intractable diseases, this research aims (i) to develop a manual which serves to needs for employment management from the standpoint of view of employers, and (ii) to show the possible ways of local supports in coordination with such employers. Specifically, we aim to make the following works; We (i) make a prototype employment management manual which is made based on the results of research of NIVR up to now, (ii) find issues and needs which employers and local supporters have in the course of conducting efforts of dissemination and utilization of the manual, (iii) make an improvement of the prototype manual reflecting the above-mentioned issues and needs and thus (iv) examine the ways for effective dissemination of the manual to employers and local supporters.

## 5. Research Methodology

To examine integrally issues of development and dissemination of the employment management manual which meets the needs of employers, in this research, we developed a prototype manual through product development and marketing methods and made necessary improvement of it according to the opinions and requests to the manual.



Outline of development of Employment Manual in this Research

### (1) Making the manual as a prototype

Based on the previous researches on the employment status of persons with intractable diseases at NIVR, we have defined effective implementations to cope with issues at typical case of employment for persons with intractable diseases, and have completed “For Employment Support for Persons with Intractable Diseases (Second edition)”. We have made this as a tentative prototype of “Manual for Employment Management of Persons with Intractable Diseases” since FY2016.

### (2) Dissemination of the prototype and grasping needs for improvement of it

For dissemination of the prototype, we have made (i) a direct action sending the prototype manuals to employers who have employed persons with intractable diseases through Hello Work and (ii) an indirect action advising the contents at seminars etc. to local supporters who support both persons with intractable diseases and employers in respective region. Taking these opportunities of spreading the manual, we have made questionnaire surveys and visit-and-hearing surveys to employers and persons with intractable diseases, and through that, we have been able to grasp necessary information and needs for improvement of the manual.

### (3) Development of a manual by improving the prototype

We collected and analyzed information of results and issues in utilizing the manual, and then, reviewed contents of the prototype in order to make the manual to serve as a good reference for employers conducting more appropriate employment management, including coordination with local supporters. Thus, we completed the final version of employment management manual. We also reviewed issues in dissemination and utilization of the prototype manual, and displayed effective ways and issues in dissemination of the manual.

## 6. Summarized Results of the Study

### (1) Making a prototype employment management manual for persons with intractable diseases

The “Manual for Employment Management of Persons with Intractable Diseases” issued under the basic policy for measures to counter intractable diseases of Minister for Health, Labour and Welfare is a necessary manual for employers to establish the work environment where persons with intractable diseases can disclose their diseases to employers without fear of the discrimination and can balance their medical treatment and work life. The necessity of such activities by employers (i.e. establishing circumstances) accords with the results of storage of analysis which NIVR has made the research to persons with intractable diseases and local supporters (i) on their work before and after employment, (ii) on their performance and (iii) on relations among various activities at workplaces and in community.

The research of NIVR up to now mainly has been made to persons with intractable diseases and local supporters, and has not been made to employers directly. The contents of the research, however, are very general which, in issues on works before and after employment, reveal the relation among (i) situations of diseases and disabilities, (ii) workplaces, (iii) community and (iv) persons with intractable diseases themselves. Accordingly, by reviewing the research result from standpoint of view of employers, we think we can show employers effective ways to cope with issues of employment management for stabilizing employment and for the continuation of employment from the stage before employment.

In this research we have interpreted the storage of research results as practical activities for employment management from the standpoint of view of employers, and have found that those covered the following information which was necessary for employers to employ persons with intractable diseases; (i) The accurate understanding of the situation of “intractable diseases” without prejudice. (ii) The situation allowing persons with intractable diseases to balance medical treatment and work life without difficulty where workload and way of workings are appropriate. (iii) The effective way of implementation of employment management for persons with intractable diseases and its practical benefit. (iv) The effective way to utilize institutions and systems of local professional support. (v) The action to counter the problem of diversity and individuality of intractable diseases.

Having made examination based on the above-mentioned information, we have completed “For Employment Support of Persons with Intractable Diseases Second edition)” and have made it as a tentative prototype “Manual for Employment Management of Persons with Intractable Diseases” from FY2026.

### (2) Needs of employers for the employment management manual

We have made a “Survey on Disseminating and Improving Manual for Employment Management of Persons with Intractable Diseases” to employers who have employed persons with intractable diseases. By showing the prototype manual to employers who have actually employed persons with intractable diseases, and by subsequent questionnaire surveys to them about their

appraisal for issues and needs of employment management for persons with intractable diseases and about their utilization and results, we have tried to reveal issues in improving the manual.

As a result, we have found the following points;

- We have received 158 responses from employers mainly of medium and small-sized enterprises. We have received from not only employers who have had experience of employing persons with disabilities but from those who have not had such experience and who are about half of the respondents. Many employers have employed persons with intractable diseases within last one year and about half of such employees have not had Disability Certificates.
- As to actual utilization of the manual, it was often utilized in situations of “Consideration after employment” and “Communication with persons with intractable diseases”. “Points of employment management” and “Points of attention for typical intractable diseases“ have been pointed out as especially useful contents. There have been many appraisals that actual utilization of the manual has served to conduct effective employment management for persons with intractable diseases and to enable persons with disabilities to conduct works as an occupation.
- There have been many requests to show contents in a manner demonstrating actual cases together with showing “ characteristics and points of consideration of each group of disease”, “successful examples of employment by companies” and “details of government systems and measures”.
- It has become clear that, especially in offices which have little experience in the employment of persons with disabilities, there is some room for improvement of the overall structure, and that there are issues of dissemination regarding the timely delivery of manual when needed.
- We could have obtained the actual cases of various devises and consideration in employment management such as (i) adjustment at ambulatory etc. after employment or job allocation which allows persons to work without excessive difficulty, (ii) communication or understanding at workplace and (iii) policy of the company, etc.

From the above-mentioned appraisals by employers who practically conduct employment management of disabilities, it is important to utilize “Points for Employment Management” and “Points of Consideration” for “Consideration after Employment” and “Communication with Persons with Intractable Diseases” in a further development of employment management manual. Moreover, it has become clear (i) that it is necessary to improve overall structure taking into account of actual needs for employment management (including needs from employers who do not have experience of employment of persons with intractable diseases and who have employed such persons for the first time) and to add necessary information, and (ii) that the issue of dissemination such as timely delivery of the manuals are also serious.

(3) Actual cases of employment management for persons with intractable diseases (Visit-and-hearing surveys)

By the above-mentioned questionnaire survey, we have been able to confirm views and requests for practical improvement. To such needs for improvement, we have found that we can meet some of such needs by storage of research results up to now and by addition or review of information on the situation of each intractable disease and on most recent systems and services. We, however, have found that it is also necessary to collect additional information about the actual endeavor of employment management by employers and the voices of employers and persons with intractable diseases.

In reference to above, we have visited actual workplaces where persons with intractable diseases are employed and have made hearing surveys on the actual endeavors and the issues of recruitment and of employment management after employment for persons with intractable diseases from the standpoint of view of both employers and persons with intractable diseases.

As a result, by listening to both employers and persons with intractable diseases about actual cases of consideration at recruitment and at workplaces and of supports for balancing medical treatment and work life, we have been able to collect much information which enables us to imagine practical employment management to meet the needs for improvement of the employment management manual;

- Cases that we can understand actual situation in which, although it is not subject to employment quota system for persons with disabilities, employers positively employ, provide reasonable accommodation, make a fair appraisal of ability for persons with intractable diseases and eventually are able to enjoy merit.
- Cases that demerit of disclosing intractable diseases at various occasions, i.e. at recruitment, after employment and at supports for leaves or reinstatement, has been overcome and that timely and effective communication between employers and persons with intractable diseases is promoted.
- Actual cases of implementation of employment management at the time and after employment in order to let persons with intractable diseases work as an occupation after employment.
- Actual cases (i) of the situation where persons with intractable diseases cannot continue the work because of illness etc. (ii) of the situation of issues of various intractable diseases at actual workplaces and (iii) of the implementation of employment management at workplaces.
- Cases which enable us to understand the situation where employers support balanced treatment and work life for persons with intractable diseases, and give consideration for their safety and health in the circumstance without the industrial physician.
- Cases of effective utilization of local related services and systems.
- Cases of utilization of know-how of employment support for persons with disabilities in the circumstance of progressive intractable diseases or in the cases where Development Disability and Intellectual Disability appear.

#### (4) Implication of employment management for the local supporting staff

Not only in the field of intractable diseases but generally, supports by local institutions of

healthcare or labor sector and implementation of employment management such as recruitment of persons with disabilities, appropriate allocation, continued supports for balancing treatment and work life, etc. by employers are two sides of the same coin. In the field of intractable diseases also, the storage of research results of NIVR consistently shows that endeavor of employment management by employers and supports from related fields are also two sides of the same coin in supports for persons with intractable diseases to continue their work without excessive difficulty balancing treatment and work life.

By recent years, however, in the research to local supporters of related fields of intractable diseases or supporters of employment, we have found actual endeavors, recognitions of role and their wishes are not strong in the fields of either healthcare or labor sector. With regard to government systems, it is after the enforcement of Intractable Diseases Act in 2015 that the position of employment support in government measures to counter intractable diseases has been officially clarified and it is only after FY2016 that provision of rational consideration to persons with intractable diseases who are not subject to employment rate system for persons with disabilities has officially become the obligation of employers. In such circumstances, it has become an urgent issue to effectively develop human resources of supporters in related fields of employment support for persons with intractable diseases.

Accordingly, it may be possible that we expect the employment management manual, which we plan to newly develop, to serve for such persons concerned to implement their support in the region effectively in coordination with employment management by employers.

In this research, we have made studies and trainings of effective employment support of intractable diseases based on the storage of research results and have grasped results and issues for developing human resources. We have thus been able to grasp the possibility and issues for the future about dissemination and utilization of the employment management manual for these local supporters.

The followings are points we could have found;

- Those supporters concerned who are legally in charge of employment support for persons with intractable diseases and are expected to attend such seminars have, from the stage before receiving training and lectures, had already a reasonable recognition of implementation points for employment support of persons with intractable diseases and also have had a reasonable recognition and intention for their role in the actual implementation.
- On the other hand, their recognition about the results and merits of work supports for persons with intractable diseases and employers of such persons has been not clear in most cases. After having received seminars and lectures based on the results of the research of NIVR, however, their recognition has become clear, and this suggests that, with the employment management manual for employers which we plan to develop in this research, seminars and lectures may be more persuasive and may serve to let them have deeper recognition.
- Moreover, issues at workplace were the most concerned by the Employment Supporters for Persons with Intractable Diseases who are expected to play the most important integrated role in community, thus related contents should be enhanced in such lectures. It has become clear that,



for enhancing such contents, the employment management manual for employers which this research plans to develop may be utilized.

#### (5) Promotion and improvement of the employment management manual for persons with intractable diseases

Based on the results of this research mentioned above, about issues on making and disseminating of the last version of manual for employment management of persons with intractable diseases which we plan to make by revising prototype manual, we have concluded as follows;

- The formerly under-mentioned points but appraised by employers of persons with intractable diseases and by local supporters to be useful should be included. Further, we should improve structure and contents of prototype (i) by making the manual meet closer to the needs of actual employment management of employers and (ii) by focusing on contents which persons concerned expect to the manual with organizational coordination with supports from local related fields which always develop, and thus we totally revised it as “Manual of Employment Management for Persons with Intractable Diseases”.

- From the storage of research of NIVR, it has become an important issue of management of company to eliminate the prejudice that “intractable diseases = cannot work / cannot support”.

The concept of enabling everybody to work at office irrespective of reason of difficulty was beyond the concept of employment and recruitment of persons with disabilities. This employment management manual aims to help employers to implement



such management issue. Practically, observing the issues such as recruitment, allocation, training, and employment management of transfer, leave, retirement, etc., of persons with intractable diseases, the manual aims to serve for examination of jobs which persons with intractable diseases can work as an occupation without excessive difficulty and for establishing such work environment. Since in many cases symptoms appear after employment, it also aims to let people consider the measures when the colleagues at workplace take leave or are hospitalized. Moreover, it aims to deal with both aspects of commonality and diversity/individuality of vocational issues of intractable diseases.

- The dissemination of employment management manual is useful not only for employers but for local supporters since it has become difficult for them to cope with various issues before and after the employment of persons with intractable diseases in coordination with employers. Not from the standpoint of view of the provider of manual, i.e. “disseminating research results” but

from the standpoint of view of users which focuses on occasions that the manual is used actually and timely for objects which have high needs for manual, the dissemination through many and various channels is important.

- In the employment support for persons with intractable diseases, the issues of the employment support for persons with disabilities, of the employment support under the measure to counter intractable diseases and of the so-called work-style reforms / balancing medical treatment and work life, are closely integrated. We expect the endeavor in every issue shows a big development in the near future. That is a common issue for developed countries where many people live with chronic disease as a result of technical development in the medical field. The employment management manual which we have developed this time will serve to the employers of persons with intractable diseases, persons themselves and regional supporters for their endeavor and will also serve to promote such human resource development. By utilizing the manual, we expect other new practical issues are recognized and the measures to cope with those issues will become another task for us.

## 7. Related Research report

Employment Management Manual for Persons with Intractable Diseases, 2018

For Employment Support for Persons with Intractable Diseases, 2016

Research on the situation of difficulty in employment by the extent of symptoms of intractable diseases and on desirable ways of employment support, Research Report No.126, 2015

For the coordination of medical treatment and work in employment support of persons with intractable diseases, 2014

Research Report on the situation of employment support for persons with intractable diseases at healthcare institutions, Material Series No.79, 2014

Research Report on the situations and issues of employment support for persons with disabilities at employment support institutions etc. who have a big difficulty in employment ~mainly of Mental Disability and Intractable Diseases ~ Research Report No.122, 2014

Research on issues of employment management and ways of employment management for persons with intractable diseases Data collection of intractable diseases, Appendix to Research Report No.103, 2011

Research on issues of employment management and ways of employment support for persons with intractable diseases, Research Report No.103, 2011

Employment support manual for intractable diseases, 2008

General research on the establishment of work life support network for persons with disabilities in coordination with local employment, medical treatment, etc. Research Report No.84, 2008

Situation of employment and issues of employment support for persons with chronic diseases such as intractable diseases, Research Report No.30, 1998