



# **Actual Situation and Issues Regarding Support for Patients with Intractable Diseases to Find Jobs and Settle into the Workplace through Collaboration between Companies and Relevant Local Organizations/Occupations**

## **(Research Report No.155) Summary**

### **[Key Words]**

Collaboration, health care institutions, support for balancing treatment and work, workshop, checklist, intractable diseases, vocational rehabilitation for patients with intractable diseases

### **[Points for Practical Purpose]**

As "support for finding jobs and settling into the workplace through collaboration between companies and relevant local organizations/occupations" has become evident as an effective form of vocational rehabilitation, we hope that this information will be used to support people with intractable diseases through collaboration and role-sharing among employment support for persons with disabilities, work support in the healthcare field for persons with intractable diseases, and support for balancing treatment and work. Three types of information tools were compiled as a product of this research to meet the needs of the interested parties.

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National Institute of Vocational Rehabilitation

## **1 Authors (in writing order)**

HARUNA Yuichiro (Acting Research Manager, Research Group on Support for Social System, National Institute of Vocational Rehabilitation)

HORI Hirotaka (Researcher, Research Group on Support for Social System, National Institute of Vocational Rehabilitation)

## **2 Research Period**

FY 2019 through FY2020

## **3 Composition of the Research Report**

Chapter 1 Background, Purpose of Research, and Overview of Methods

Chapter 2 The Challenges and Feasibility of Implementing Vocational Rehabilitation through Community Collaboration for Persons with Intractable Diseases

Chapter 3 Creating Information Tools for Interested Parties

Chapter 4 Comprehensive Considerations and Conclusions

Appendix

## **4 Background and Purpose**

In these years, effective vocational rehabilitation for physical, intellectual, and mental disabilities has been comprehended as "support for finding jobs and settling into the workplace through collaboration between companies and relevant local organizations/occupations". Although vocational rehabilitation for persons with intractable diseases is still developing, their specific issues in support for finding jobs and settling in the workplace through collaboration between companies and relevant local organizations/occupations have become clearer based on surveys and analyses conducted on persons with intractable diseases, support organizations, employers, etc. On the other hand, work support for persons with intractable diseases has been promoted as a new challenge, not only in the field of employment support for persons with disabilities, but also in the field of work support in the healthcare sector and support for balancing treatment and work for intractable diseases. However, their effective collaboration tends to be difficult due to differences in the objectives and frameworks of support among the various fields.

The purposes of this research are to comprehensively grasp the actual situation and issues of the approaches taken by the various parties involved in supporting persons with intractable diseases to find employment and settle in the workplace, and to create pamphlets and other materials (work support utilization guides and leaflets) that becomes a map for promoting effective role sharing and cooperation among the various parties involved, and a handbook to

be utilized as a practical manual of vocational rehabilitation for persons with disabilities by local vocational centers for persons with disabilities, as "information tools for involved parties" based on the research results.

## 5 Method

National Institute of Vocational Rehabilitation (hereinafter referred to as "NIVR") has provided not only those involved in employment support for persons with disabilities, but also those in health and medical care involved in work support for persons with intractable diseases, with information about work support needs of people with intractable diseases and ways to provide effective support based on the research, as well as information on the status of system development during professional trainings. This time, after such professional trainings, we surveyed each of them to understand their feasibility of offering concrete support and their implementation issues.

In addition, workshops by public invitation were held to further understand the specific support needs of other healthcare institutions, professionals with intractable diseases, people involved in employment support for people with disabilities and intractable diseases. By simulating a scene of cooperation among multiple organizations and professions in the community through group work, etc., we were able to assess the feasibility of providing various types of support and the implementation issues through questionnaires from the participants.

Table 1 Training programs and workshops where practical issues in employment support for people with intractable diseases were identified for this research

Public Invitation	Main Participants	Number of Participants	Objectives of the training/workshop	Composition
	Staff of Public Employment Security Office	53	Training on employment support for persons with disabilities	Lecture 110 min.
○	Practitioners at Intractable Disease Consultation Support Center, officials in charge of intractable disease administration, Vocational Centers for Persons with Disabilities	37	Network Training for Intractable Disease Consultation Support Center	Main lecture 70 min. Group work 180 min.
	Counselor for daily life and employment support staff at the Intractable Disease Consultation Support Center	15	Training for Supporters at Intractable Disease Consultation Support Center	Main lecture 60 min. Group work 180 min.
	Health Practitioner for Intractable Diseases	66	Training for Health Practitioner for Intractable Diseases	Lecture 60 min.
○	Employment and living support centers for persons with disabilities, employment support offices for persons with disabilities, intractable disease patients associations, MSW, persons with intractable diseases and their families, welfare service providers, vocational	25	Considering the possibility of utilizing telework for persons with intractable diseases	Main lecture 60 min. Group work 90 min.

	centers for persons with disabilities			
○	Medical institutions for intractable diseases, staff in charge of workplaces, occupational health professionals, people with intractable diseases, support for balancing cancer and work, and Vocational Centers for Persons with Disabilities	40	Support for balancing treatment and work through collaboration among medical institutions for intractable diseases, workplaces, and occupational health professionals	Main lecture 60 min. Group work 180 min.
	Intractable Disease Consultation and Support Center, MSW, public health nurses for people with intractable diseases, social insurance labor consultants, Employment and Life Support Centers for Persons with Disabilities, public employment security office, people with intractable diseases and Vocational Centers for Persons with Disabilities	50	Networking and training of local people involved in supporting people with intractable diseases to find jobs and settle into the workplace	Main lecture 60 min. Group work 180 min.
○	MSWs at medical institutions for intractable diseases, Occupational Health Centers, Intractable Disease Consultation and Support Centers, public employment security office, people with intractable diseases and Vocational Centers for Persons with Disabilities	60	Role-sharing and cooperation between integrated consultation and support for treatment, daily life and work, and support for balancing treatment and work at medical institutions	Main lecture 60 min. Group work 180 min.

The information tools for involved parties were developed based on the participants' intentions and their specific practical issues identified through these efforts, and finalized after hearing opinions of the involved parties and adjustments.

## 6 Research Content

### (1) Professional Training and Role Sharing/Collaboration Workshops for Supporting Employment and Balancing Work with Intractable Diseases

From the questionnaire survey conducted on the participants of the professional training and workshops, we categorized the answer contents of "What I would like to work on myself and its effects" and "What needs to be worked on by relevant local organizations, companies, and government in the future". We further organized the contents using principal component analysis, and as a result of canonical correlation analysis of the relationship between each principal component, we were able to confirm two statistically significant canonical correlations. The relationship was independent of the differences in professional training and workshops, and was based on the proactive intentions of the organizations and professions involved, and clarified challenges in implementation that exist regardless of such intentions. It also clarified issues related to future system development and information tools which were the purpose of this study.

Table 2: Reorganization of the first and second canonical correlations that were significant in the canonical correlation analysis of "What I would like to work on myself and its effects" and "What needs to be work on by relevant local organizations, companies, and government in the future"

What many professional supporters want to work on		What I would like to work on myself and its effects" and "What needs to be worked on by relevant local organizations, companies, and government in the future"
Healthcare fields refer mainly those with mild diseases to appropriate work support and support for balancing work and treatment (first canonical correlation +)		Unable to understand the situation that needs to be referred during medical and life consultation support sessions
		To improve the results of work support according to the characteristics of intractable diseases by connecting medical and lifestyle consultation support to the field of work support
Employment support that can be provided in the healthcare sectors	Provide early employment support for patients with progressive intractable diseases in the medical setting (1st canonical correlation -)	Consideration of support for balancing work and treatment in cooperation with the primary physician based on the nature of the work at the job hunting stage (Development of employment consultation services in the healthcare sector, such as on-site consultation by supporters of employment for persons with intractable diseases)
	Engage in support for balancing treatment and work for patients with intractable diseases who are currently working, which includes explanations of medical information (2nd canonical correlation +)	
Community-wide efforts, including finding new place of employment for people with intractable diseases where they can balance treatment and work without difficulty with corporate awareness (2nd canonical correlation -)		Role sharing and collaboration based on a common understanding of the work support needs among local supporters in various fields and persons with intractable diseases

Analysis of the questionnaire responses showed that by providing information on employment support needs and how to provide effective support, we were able to increase the willingness of local stakeholders, including those in the health and medical fields, to share their roles and collaborate based on their respective expertise. However, it became clear that as they thought of more specific practices, they became aware of many challenges they might be facing.

- Through lectures and presentations, it was newly recognized that there are needs for employment support for people with intractable diseases that have not been fully recognized in the past due to the fact that they are "mildly ill" and not subject to the disability certificate system. Additionally, the importance of job selection and ensuring that they receive necessary accommodations in the workplace was recognized. As a result, many expressed their intention to play roles in proper referral of persons with disabilities to employment support for persons with disabilities and support for balancing treatment and work from healthcare sector, early response and explanation of medical information in the healthcare sector, and the development of employment opportunities for persons with intractable diseases by raising awareness and disseminating such information to society as a whole including companies.
- On the other hand, the following issues were raised as issues that need to be addressed in the future by local organizations, companies, and governments, in response to their respective intention to take action.

- **Response to Work Support Needs in Medical and Daily Life Consultation Support Situations:** It is difficult to determine under what specific circumstances people with intractable diseases should be referred to employment support or support for balancing treatment and work during medical and lifestyle consultations in the healthcare field.
- **Vocational Rehabilitation with or without Disability Certificate:** It is hard to implement effective vocational rehabilitation support (vocational consultation, job referrals, job evaluation, job preparation support, employer support, etc.) for persons with intractable diseases who do not have a disability certificate, even if they are referred from the healthcare field to the employment support field for persons with disabilities.
- **Effective Collaboration with Support for Balancing Treatment and Work:** Regarding the support for balancing treatment and work, the flow of communication and cooperation among primary physicians, occupational physicians, workplaces, and the patients themselves, as well as points to keep in mind, and formats, have been established, but these can only be applied after employment. Similarly, in employment support even before employment, the agenda is to obtain a written opinion from the attending physician based on the nature of the work, etc., so that support can be provided on the premise of a smooth transition to support for choosing work and balancing treatment and work after employment.
- **Establishing a System of Collaboration among Local and Relevant Organizations and Professions:** In this workshop, we were able to examine how to share roles and collaborate with relevant local multidisciplinary organizations that can respond to the employment support needs of people with intractable diseases. However, in actual communities, there will be challenges in promoting communication among various relevant organizations, professionals, and people with intractable diseases in the future.

## (2) Create Information Tools for Relevant Parties

Based on the intentions of relevant parties and the specific practical issues identified in the previous section, three types of tools for providing information to relevant parties were developed to effectively resolve the issues, with the target audience and contents as shown in Table 3. The specific contents of the report were prepared by combining information from the NIVR's previous studies provided in lectures and presentations, the intentions and issue recognition of each institution and occupation in this study, and the opinions and content adjustments made by individuals with practical experience and policy makers in each field.

Table 3: Three Information Tools Created for Each Target Group and Purpose based on the Results of this Research

Title of Information Tool	Guide for Utilizing Employment Support for Persons with Intractable Diseases	Available Now! Support for Employment and Balancing Work and Treatment for Persons with Intractable Diseases	Vocational Rehabilitation for Persons with Intractable Diseases Handbook Q&A
Format	Pamphlet (20 pages)	Leaflet (4 pages)	Booklet (about 100 pages)
Main Target Audience	Staff engaged in medical and lifestyle consultation support in the healthcare sector	A wide range of relevant people involved in consultation support for intractable diseases	Supporters specialized in supporting the employment of persons with disabilities
Goals	To link consultation support in the healthcare sector with necessary support for employment of persons with disabilities and support for balancing treatment and work	Develop a common understanding that will serve as a trigger for dialogue among relevant parties in the region.	Providing effective support to persons with intractable diseases, regardless of whether they have a disability certificate or not
Corresponding Main Issues	Responding to the needs for work support in medical and lifestyle consultation support settings	Developing a system of cooperation among local relevant organizations and occupations	<ul style="list-style-type: none"> <li>• Vocational rehabilitation with or without a disability certificate</li> <li>• Effective collaboration with the program to support balancing treatment and work</li> </ul>

A. "Guide for Utilizing Employment Support for Persons with Intractable Diseases"

Targeting "Staff engaged in medical and lifestyle consultation support in the healthcare sector," we created a 20-page pamphlet as an information tool to solve the issue of "linking consultation support in the healthcare sector with necessary support for employment of persons with disabilities and support for balancing treatment and work".

By introducing the employment support needs of people with intractable diseases that have been provided in lectures and presentations and the status of efforts to support the employment of people with intractable diseases in related fields, we aim to increase the motivation of those involved in the healthcare field to work on employment support for people with intractable diseases. Also, a checklist is provided to be used by the readers to identify the needs for employment support in consultation and support situations in healthcare sectors, and guides are provided to connect these needs to appropriate specialized support. Furthermore, specific details of systems and support in related sectors and how to utilize them are indicated.



○ Providing Information to Boost Willingness to Engage in and Collaborate on Employment Support

Since many supporters in the healthcare field expressed that, through these lectures and presentations at professional trainings and workshops, they recognized for the first time the

needs of employment support for people with intractable diseases and the importance of coordination with employment support for persons with disabilities and support for balancing treatment and work, this guide also presents the details in an organized manner at the beginning.

○ A Guide for Collaboration based on the Understanding of the Support Needs of Persons with Intractable Diseases

Since the contents of consultation with persons with intractable diseases covers a wide range of complex issues related to medical care, daily life, and employment, it is not only difficult but also inappropriate to present a uniform approach for role sharing and collaboration. This guide rather focuses on the proper understanding of the contents of individual consultations and support needs, and shows how to connect the related organizations and professionals necessary to resolve these issues to provide effective support. To be more specific, in three steps, based on the understanding of the individual employment support needs of people with intractable diseases, it indicates how to promote the division of roles and collaboration among employment support for people with disabilities, support for balancing treatment and work, and employment support in the healthcare field for intractable diseases.

B. "Now, Available! Support for Employment and Balancing Work and Treatment for Persons with Intractable Diseases"

A four-page leaflet was created as an information tool to promote "Development of a common understanding that will serve as a trigger for dialogue among relevant parties in the region" targeting "a wide range of relevant people involved in consultation support for intractable disease."



This leaflet lists the employment support needs of people with intractable diseases that have been presented in lectures and presentations at professional trainings and workshops, as well as the

status of related systems, services, and information provision to meet these support needs. In addition, as a trigger to gain a common understanding among those involved, detailed information on the use of support and the sources of information can be found on the website.

C. "Vocational Rehabilitation for People with Intractable Diseases: Handbook Q&A"

A 100-page booklet was prepared as an information tool for "supporters specialized in supporting the employment of persons with disabilities" to enable them to "provide effective support to persons with intractable diseases, regardless of whether they have a disability certificate or not." As for local organizations in charge of vocational rehabilitation, we assumed employment support organizations for persons with disabilities, such as local vocational centers for persons with disabilities, public employment security office, and employment and life support center for persons with disabilities, as well as consultation support centers for persons with



intractable diseases and work transition support providers, which are actively involved in employment support for persons with intractable diseases in the community.

In order to be able to respond to the employment support needs of persons with intractable diseases as a core of local relevant organizations, this booklet covers not only "vocational rehabilitation with or without a disability certificate" but also "effective collaboration with support for balancing treatment and work", "responding to employment support needs in medical and lifestyle consultation support scenes", and "establishing a collaboration system among local relevant organizations and professions" so that they can work together with a common understanding, and enable to advise and assist local related organizations. The specific contents are presented in the following three chapters and materials at the end of the book in a Q&A format.



- Learning the Diverse Employment Support Needs of Persons with Intractable Diseases (Chapter 1)

With regard to the fact that persons with intractable diseases have employment support needs even if they are not under the scope of the disability certificate system, this chapter explains the situation in which, thanks to medical advances, many persons with intractable diseases are able to choose appropriate jobs while continuing treatment, and are able to play an active role in their occupations and participate in society if they can obtain understanding and accommodations in their workplaces. It also explains the needs for persons with intractable diseases to find a job where they can comfortably take an active role while balancing treatment, and to work continuously with the necessary hospital visits and physical condition management through understanding and accommodations at their workplace as well as the necessity of vocational rehabilitation corresponding to the support needs of companies that employ persons with intractable diseases.

- Understanding the Variety of Specialized Supports that Can Meet the Support Needs (Chapter 2)

This chapter informs about the progress being made in the development of consultation support in the health and medical fields, support for employment of persons with disabilities, and support for balancing treatment and work to meet the support needs of persons with intractable diseases and companies and workplaces that employ persons with intractable diseases. Also, it explains how the employment support needs of people with intractable diseases can be met by understanding the expertise and limitations of these various support organizations and support systems and how to effectively use them.

## ○ Meeting Unique Individual Support Needs by Effectively Utilizing a Variety of Specialized Support (Chapter 3)

Like the "Guide for Utilizing Employment Support for Persons with Intractable Diseases," this booklet makes it easier to understand the employment support needs that are effective in resolving typical employment consultations for persons with intractable diseases, and provides information that supports the smooth implementation of these practices, based on the premise of role-sharing and collaboration among employment support for persons with disabilities, support for balancing treatment and work, and employment support in the healthcare sector for intractable diseases.

### (3) Overview and Conclusion

As "support for finding jobs and settling into the workplace through collaboration between companies and relevant local organizations/occupations" has become evident as an effective form of vocational rehabilitation, this research clarified the actual situation and challenges that local supports face in order to put it into practice through collaboration and role-sharing among employment support for persons with disabilities, work support in the healthcare field for persons with intractable diseases, and support for balancing treatment and work.

By providing information in professional training and workshops based on the NIVR's empirical research on effective support details that can fulfill the support needs of persons with intractable diseases and employers who employ persons with intractable diseases, the willingness of local relevant parties, including those in the healthcare sector, to work on role sharing and collaboration based on their respective specialties increased. On the other hand, regardless of such intentions, it became clear that there are following specific implementation issues: (1) meeting the needs for work support in medical and lifestyle consultation support scenes, (2) vocational rehabilitation regardless of whether or not the person has a disability certificate, (3) effective collaboration with support for balancing treatment and work, and (4) building a collaboration system among local related organizations and occupations.

As tools that can respond to the implementation issues of those involved, we have developed a guide for active utilization of employment support for those in charge of medical and lifestyle consultation support, leaflets for the dissemination at local contact points, and a handbook that facilitates practical implementation of vocational rehabilitation for people with intractable diseases by local vocational centers for persons with disabilities, etc..

In the future, in order to enable persons with intractable diseases to find jobs where they can play active roles as they comfortably balance work and treatment, and to continue to work while making necessary hospital visits and managing physical conditions with understanding and accommodations at their workplaces due to the dissemination and use of these information

tools, it is important to establish local support systems and the human resource development of those involved, as well as to verify the effectiveness of specific support and to collect and disseminate good practices based on the accumulated support cases.

## **7 Relevant Research Outputs**

Guide for Utilizing Employment Support for Persons with Intractable Diseases, 2021

Available Now! Support for Employment and Balancing Work and Treatment for Persons with Intractable Diseases, 2021

Vocational Rehabilitation for People with Intractable Diseases: Handbook Q&A, 2021