



Developmental Study on Informative Supports for Relevant Community Institutions to Conduct Work Supports

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3. Contents of the survey report

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4. Background and purpose of the survey

Besides work supports by conventional labor establishments for persons with disabilities, community collaboration are under way through various programs to help persons with disabilities become independent in life and work. Such collaboration entails the areas of health and medical treatment, welfare, education and labor. Moreover, work supports are not only for individuals with disabilities but also for employers, the families concerned and relevant community institutions.

Under these circumstances, information-related challenges are now emerging in community institutions to make judgments and decisions to provide work supports.

- Professionals of different specialty use different terminology with different frameworks of concepts and quantities of specialized knowledge, resulting in differences in understanding and responses to the same phenomena.
- Employees with disabilities and the employers must both go beyond their barriers of understanding to reach a common understanding how the person can be a good employee with disabilities.
- Even regarding the most fundamental understanding of the employability of persons with disabilities, there is a wide disparity and subjective understanding in concerned persons.
- While it is important for the people concerned to share information in order to form a common understanding, it is necessary not only to comply with the Private Information Protection Law and related regulations, but also give the most prudent consideration to privacy, since information about disabilities and diseases is likely to cause misunderstandings and prejudices.

This study therefore aims to clarify and indentify the necessity and the challenges of collaborations and information-sharing beyond specialty areas and organizational borders of relevant establishments engaged in work supports in the community, and determine the ideal vision for informative support tools used in relevant community institutions toward addressing those challenges.

In this study, "informative supports" are defined as supports improving the effectiveness of manner of

acquiring and using information, that is, accumulating, transmitting and using information to effectively convey judgments and decisions necessary for work supports and community collaboration.

5. Method of the survey

A mail survey using questionnaire was conducted to determine the real situations of collaboration and information-sharing in terms of independent-living and the work supports provided by community institutions in medical treatment, welfare, education and other relevant areas. The survey was conducted for the community institutions regardless of the type of disability, and the percentage of responses collected was 32% (out of 1,987 institutions). Moreover, based on those findings, a prototype for informative support tools was developed to help the relevant community institutions collaborate, thereby considering the feasibility of informative supports.

6. Findings of the field study

It was found that there are close human relationships (face-to-face relationship) among the persons responsible at Disability Work-Life Support Centers, Work-Transition Support Providers, at Special-Needs Schools in order to meet the integral needs of persons with disabilities to work and independent-living. It was also found that information is shared mainly through case meetings and in daily oral communications. Efforts are being made to protect personal information (although some challenges remain to be addressed). And the persons concerned are highly conscious of the ethical challenge of sharing disability information for proper use and against misuse creating harm. The institutions now less involved in the work support network had needs of educative/instructive materials and tools for work supports as informative supports, while institutions as the center of the network had needs of practical tools to share information more effectively.

(1) The present condition of collaboration and information-sharing to support vocational life with the entire community (Part I)

In the community collaboration for work supports through various programs, how do the professionals in various areas cooperate beyond their specialty, and what purpose and degree of information-sharing among them? Our field survey revealed the following:

- In communities, institutions designed to help independent-living and work of persons with disabilities are increasingly developing cooperative and collaborative relationships among themselves. More specifically, Disability Work-Life Support Centers, Work-Transition Support Providers, Special-Needs Schools are integrally working to support independent-living and work of these persons. In those efforts, the persons responsible are increasingly sharing information among themselves through "face-to-face relationship" (Chapter 1)
- At present, in order to provide effective work supports, relevant community institutions have acquired wide-range of information regarding impairments and diseases, vocational wishes and aptitudes, challenges in various aspects of vocational life, jobs that may meet the wishes, perspectives for supports and accommodations from employers and colleagues, supports provided by community institutions, and efforts made by persons themselves. Those information is necessary for case management efforts and making highly professional judgments on such issues as "supports required for obtaining a job and remaining employed, and their effects." (Chapter 2)

(2) Compatibility of Close Information-Sharing and Legal and Ethical Challenges (Part II)


In their efforts of close collaboration, how do relevant community institutions comply with their confidentiality obligations for handling personal information about persons with disabilities, comply with the Personal Information Protection Law, and address other ethical challenges? And what kinds of challenges are involved? Regarding those issues, our field survey revealed the following:


- Information-sharing at relevant community institutions to provide work supports is based on daily

communications through talks and telephone conversations among the persons concerned, and through case meetings and other conferences. These efforts endorse community collaboration based on "face-to-face relationships." The demand for sharing information in writing is rather high, but such a practice remains limited. (Chapter 3)

Table: Collaborative scenes where personal information must be shared at Disability Work-Life Support Centers

Examples of collaborative scenes where information must be shared	Conducted without problems	Conducted but with some problems	Wish to do so but cannot	Do not do so, no need to do so
Official collaborative meetings such as case meetings with relevant institutions	54.2%	39.3%	4.7%	0.0%
Daily communications among the persons responsible	65.4%	30.8%	2.8%	0.0%
Use of evaluation/diagnosis etc. owned by persons with disabilities themselves	39.3%	49.5%	8.4%	0.9%
Sharing of records and other documents with designated institutions	27.1%	43.0%	23.4%	3.7%
Voluntary provision of information by other institutions	27.1%	51.4%	17.8%	1.9%
Provision of information in response to information requests	37.4%	51.4%	7.5%	1.9%

Results of chi-squared test:  : High on 1% level

 : High on 5% level

Numbers in italics: Low on 5% level

- It became clear that community institutions face many challenges regarding the sharing of personal information, with their response to ethical issues being regarded as insufficient. Moreover, efforts to share information appropriately were regarded as closely linked with the appropriate storage of personal information, acquisition of comprehensive consent from persons with disabilities, and response to ethical issues about disability information. (Chapter 4)

(3) A vision for informative support tools fitting the needs of community institutions (Part III)

In collaborative scenes beyond the silo of specialties to support independent-living and work, what kinds of informative support tools do the supporters and institutions require? And how can one meet such needs? Regarding those issues, our field survey revealed the following:

- The demand for informative support tools was high in general regardless of the type of relevant community institution, when including "very much in demand" and "may become necessary." General trends indicated that, institutions less experienced in work supports showed much demand for educative and instructive informative supports regarding efforts for work supports, while institutions playing a core role of work supports in their communities showed high demand for informative supports designed to address the challenges of specific collaboration and information-sharing in those communities. It is necessary to distinguish between such diverse needs for informative supports to develop appropriate informative support tool. (Chapter 5)

7. Critical points of acquiring and using information

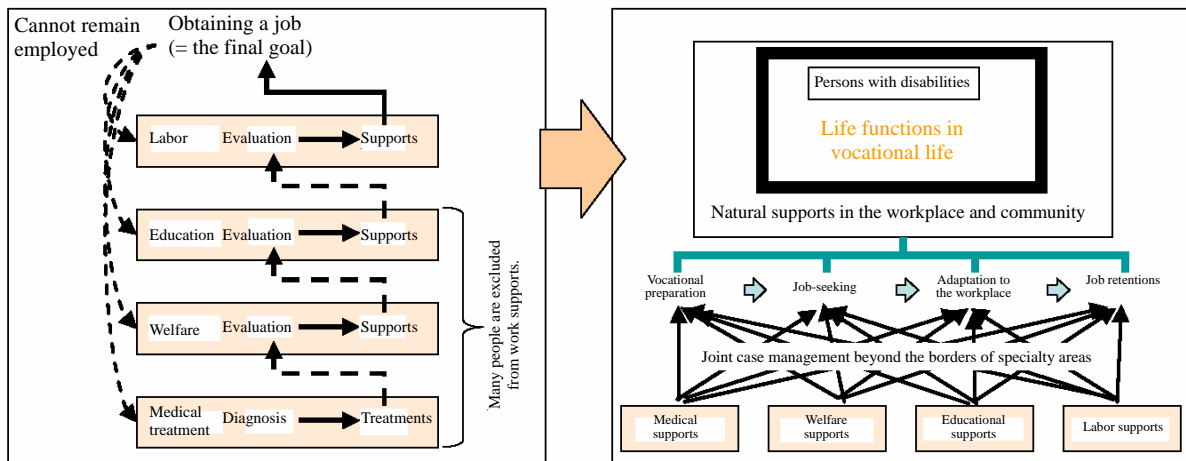
In communities today, the way of evaluation and providing supports is changing from the conventional way within specialty silos, to collaborative case management centering on the needs of persons with

disabilities. As the changes are developing, supporters and institutions are facing many challenges regarding information due to the limitations of conventional efforts. Moreover, the supporters and institutions engaged in this new kind of community collaboration and work supports centering on persons with disabilities are facing the challenge of developing a new system, tools and other resources for common understanding.

(1) Necessity of "individual", "on-going" and "cross-fields" information

At present, many efforts are being made to support the daily life and lifelong course of persons with disabilities in an individualized and on-going manner in various areas. Consequently, work supports are becoming a common challenge for medical treatment, welfare, education and labor as supports for persons with disabilities in their "vocational life" from the time before they get a job until after they get a job.

Main institutions helping independent-living and work of persons with disabilities enjoy cooperative and collaborative relationships, and the persons responsible share information closely through "face-to-face relationships." The sharing of information by relevant institutions is in fact something to be grasped in its entirety where the various persons responsible and specialists in the entire community help independent-living and work of persons with disabilities.



Persons with high difficulty in working life needs the efforts of a case management and professional judgments such issues as "supports required for obtaining a job and remaining employed, and their effects." Institutions doing work supports need close joint work toward the independent-living and employment of persons with disabilities, with sufficient awareness of the legal and ethical challenges in handling disability information. It is important to promote a comprehensive understanding of individualized working life for each person with a disability among the persons, employers and supporters, as well as to prevent fragmental information from going around unchecked. That is indispensable not only to ensure an appropriate response to legal and ethical challenges, but also to ensure effective work supports.



People involved in work supports should carefully handle disability and personal information, as well as promote information-sharing in order to provide work supports for those persons, with consent obtained from persons with disabilities and confirming the purpose of the sharing and the reliability of the people concerned. To realize such efforts more appropriately, it is necessary to determine an effective system for joint use of information among institutions and proper methods of implementing "informed consent" from persons with disabilities.



Based on the research results, "Guidebook for acquiring and using information in community work

supports" was developed as one proposal of comprehensive informative support tool designed to integrally support work supports, community collaboration and information-sharing among community institutions.

(1) Expected readers

The readers of this guide are expected to be any supporters who support working life of persons with disabilities in communities and face challenges with the acquisition and information-sharing, regardless of their specialty (such as health and medical treatment, welfare, education and labor). The field survey indicates that the needs of such supporters can be roughly divided into two categories. The guide was therefore designed to meet both categories of the needs.

- a) For supporters who seldom join the community work support network
Many institutions, despite the shortage of information about work supports, have recently begun tackling work supports in order to meet the needs of persons with disabilities or diseases for independent-living and work. For those supporters of such institutions, this guidebook presents a method of acquiring and using information effectively by joining the community work supports network, in order to help independent-living and work of persons with disabilities or diseases.
- b) For supporters who already provide supports in the work supports network
For institutions that have already built or joined a community work supports network and are challenging information-sharing among institutions, the guidebook presents a way of information sharing for effective work supports, appropriately addressing the legal and ethical challenges.



(2) Composition of the guidebook

The guidebook is constructed as a comprehensive informative support tool to summarize the acquired and used information into the set of common document forms usable among institutions, and designed to share a common understanding for work supports among persons with disabilities, their families and the supporters at corporations and communities. The guidebook gives an overview of information needed in work supports and community collaboration and information-sharing for work supports. And it also addressed legal and ethical challenges in sharing information, and provides concrete common forms for sharing information. The guidebook describes the following themes:

- Work supports and information
- Acquiring and using information for work supports
- For appropriate information sharing
- Use of a collection of common forms
- A collection of common forms

9. Conclusion

Conventional efforts of evaluation and supports for persons with disabilities within the silos of specialty (such as health and medical treatment, welfare, education and labor) have tended to result in a vicious circle, where incomplete supports based on fragmental information about "Functioning" and an incomplete understanding based on them results in underestimation of the employability of persons with disabilities and prejudices that they "cannot work." And those prejudices further hamper public response to the employment needs of persons with disabilities in various specialty areas. In various parts of the country today, many joint efforts are being made beyond the borders of specialty areas to overcome those limitations and help persons with disabilities in their daily life and lifelong course in an individualized and on-going manner. As those institutions arrange a system for sharing information appropriately, community collaboration is promoted beyond specialty areas and institutions, thereby increasing the comprehensive understanding of the possibilities of work supports among persons with disabilities, employers and supporters. As a result, the significance of sharing information for work supports becomes even clearer. From now on, it will be necessary to follow this good circle for promoting the efforts of community collaboration, work supports and information-sharing in each area of specialty.

