



Study on the Issues of Work Support for Person with Developmental Disabilities

[Survey Report No. 88] Summary

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Overview, Introduction, Part I, Chapter 1, Part 1, Chapters 3 and 4, Part II, Conclusion

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2. Research period

Fiscal 2006 to 2008

3. Composition of the survey report

This report centers around persons with pervasive developmental disorders and learning disabilities covered by the Law for Assisting Persons with Developmental Disabilities (e.g., autism, Asperger's syndrome and other pervasive developmental disorders, learning disabilities, attention-deficit hyperactivity disorder, similar cerebral function disorders having symptoms designated in governmental ordinances as something that usually appears at a young age), and considers work supports focusing on the "Shift from school to work" and "Current situation of entering into work and designing a life career." This report pertains to such research challenges and consists of Part I (a field survey report) and Part II (a hearing survey report).

Part I covers three surveys of the actual conditions of adults with Developmental disabilities. Chapter 1 describes "A Field Survey of Youths and Adults with Developmental Disabilities at Work and in Their Daily Life" (a survey planned by the NIVR) and reports the responses made mainly by persons related to Autism Society Japan. Chapter 2 describes "A Field Survey on the Shift from School to Work" (a survey planned by Japan Parents' Associations of Learning Disabilities) and uses the same questionnaire form to report the results of surveys conducted at two points in time three years apart. Chapter 3 describes "A Survey of How Work Support Facilities Are Used for Youths with Developmental Disabilities" (a survey planned by the NIVR) and reports the responses made by the supporting establishments.

Part II covers a survey of cases where the actual conditions of adults with developmental disabilities were considered. To that end, in addition to "A Field Survey of Youths and Adults with Developmental Disabilities at Work and in Their Daily Life" conducted in Part I, Chapter 1, a report was made on cases with pervasive developmental disorders in response to the hearing survey of such persons with disabilities or their families, and who did not select vocational rehabilitation service upon their graduation. The cases collected here consist of employed persons, job-seekers (unemployed) with experience of leaving work and/or obtaining another job, and persons without work experience (graduated from school but not obtaining a job).

4. Background and purpose of the survey

The purpose of this survey is to monitor the actual situations of adults with disabilities at work or in welfare work etc, and consider the challenges faced by persons with Developmental disabilities in work supports regarding the use status of work support establishments, educational establishments, life support establishments and related establishments. To that end, we conducted "A Field Survey of Youths and Adults with Developmental Disabilities at Work and in Their Daily Life" [a survey of involved persons of an association of persons concerned (with autism or learning disabilities)] and "A Survey of How Work Support Facilities Are Used for Youths with Developmental Disabilities" (a survey of facility supporters). Moreover, through case studies, we considered the actual conditions of persons with pervasive developmental disorders who did not select vocational rehabilitation when they graduated.

5. Method of the survey

Questionnaire survey:

- (1) "A Field Survey of Youths and Adults with Developmental Disabilities at Work and in Their Daily Life" (a survey of involved persons of an association of persons concerned)
- (2) "A Survey of How Work Support Facilities Are Used for Youths with Developmental Disabilities" (a survey of facility supporters)

Hearing survey: A survey of persons who cooperated with (1)

"A Field Survey of Youths and Adults with Developmental Disabilities at Work and in Their Daily Life" was initially designed as a survey for members of an association of involved persons and planned to be conducted in fiscal 2007 for Autism Society Japan, Japan Parents' Associations of Learning Disabilities and other associations. However, the survey conducted by Japan Parents' Associations of Learning Disabilities was scheduled for a time immediately after "A Field Survey on the Shift from School to Work" of 2006, which is conducted every three years by that society and happened to coincide with the compilation of the findings. A decision was therefore made to postpone the survey planned by the NIVR scheduled for fiscal 2007. For that reason, after the report on the findings was made to the members by Japan Parents' Associations of Learning Disabilities (in December 2008), it was decided that the NIVR would request compilation of this report and consider matters to fulfill the earlier purpose regarding the portion of the survey related to "A Field Survey of Youths and Adults with Developmental Disabilities at Work and in Their Daily Life." Therefore, "A Field Survey of Youths and Adults with Developmental Disabilities at Work and in Their Daily Life" was conducted for the persons involved, centering on members with the cooperation of Autism Society Japan.

6. Contents of the survey

- (1) Overview of the questionnaire survey

- 1) The status of youths and adults with developmental disabilities

The two surveys for the associations of persons involved revealed the following:

[Survey for Autism Society Japan and other persons involved: Planned by the NIVR]

| | |
|------------------------------------|--|
| Overview of the persons surveyed: | A total of 1,078 persons responded to 4,236 questionnaire forms sent out (for a collection rate of 25.4%). |
| Age composition: | Combining the group of persons in their 20s accounting for 40% and those in their 30s accounting for a little less than 40% totals a little less than 80%. |
| Status of educational backgrounds: | Users from schools for children with disabilities (today's special-needs schools) account for 66%. |
| Use status of the support program: | Holders of a beneficiary certificate for receiving services for the mentally disabled account for 84%. Conversely, non-holders of physical disability certificates account for 5%. Beneficiaries of basic disability benefits (aged 20 and older) account for 89%, including those who have filed applications but have yet to receive the benefits. |

Present status: Those "using welfare facilities" account for 70%—the highest percentage. Of those, that "commuting there" account for 43%, while those who "entered there" account for 22%, and those unspecified about "commuting there or entered there" account for 5%.

Those with a "regular job in a company" account for 12%, while those "self-employed, free-lance, part-time, engaged in contract work or otherwise with short-time or short-period work, providing help in domestic chores, or otherwise engaged in non-regular work" accounted for 4%.

Those "housewives or househusbands with no outside work, unemployed or otherwise staying home" accounted for 6%, while those "in school" accounted for 5%.

Those in the category of autism were diagnosed with what can be collectively referred to as pervasive developmental disorders, but were actually given various names for their disabilities such as autism, highly functional pervasive developmental disorders, highly functional autism and Asperger's syndrome. This reflects the diversity of characteristics. On the other hand, the reality is that the diverse names of such disabilities and characteristics make it difficult for society, corporations and other parties receiving persons with disabilities to understand the situation.

[Survey for members of Japan Parents' Associations of Learning Disabilities in 2006: Planned by Japan Parents' Associations of Learning Disabilities]

Overview of the persons surveyed: A total of 430 persons responded to 644 questionnaire forms sent out (for a collection rate of 66.8%).

Age composition: Those in their 20s account for 70%. The respondents center on young ages with the peak at age 19.

Status of educational backgrounds: Users from schools for children with disabilities (today's special-needs schools) account for 16%.

Use status of the support program: Holders of a beneficiary certificate for receiving services for the mentally disabled account for 46%. Likewise, non-holders of disability certificates also account for 46%. Beneficiaries of basic disability benefits (aged 20 and older) account for only 43%, even when including those who have filed applications. In contrast, those who have not applied for basic disability benefits account for 54%.

Present status: Those "in school" account for 23%—the highest percentage. Those "at work as person with disability (no less than 20 hours a week with special assistance as an employment measure) account for 22%. Those "at work on a general basis (with more than 20 hours a week) account for 20%. Those "on a part-time basis (with less than 20 hours a week, working at general business places)" account for 4%. Those "at home (including commuting dormitories and group residences), engaged in volunteer work or hospitalized, etc." account for 12%, while those "using vocational aid and other facilities" account for 12%. Those "in vocational training" accounted for 7%.

Some persons aimed to obtain a job on a general basis but "failed to obtain a job." Some did obtain a job but "experienced inadaptability at work," "lost the job" or underwent a similar experience, sought medical treatment, and were diagnosed as being disabled. These cases presumably need early diagnosis or early response and, regarding job selection, require the development of an assistance system that allows them to select vocational rehabilitation as necessary.

Post-graduation life scenes are not necessarily provided with assistance that meets the disability characteristics of the person involved. These circumstances cause mental instability, loss of motivation and various other forms of inadaptability, sometimes resulting in persons with disabilities being obliged to change their career path. Some were even placed on a waiting list for use of the facilities and other means. It has been made clear that the shift from welfare to employment and related activities takes a long time. In parallel with the development of a reception system at corporations, along with related understanding and education, the way must be paved for assistance establishments that support the lives of persons with disabilities.

- 2) Use status of establishments related to youths and adults with developmental disabilities
The survey of related establishments revealed the following:

Overview of establishments surveyed: A total of 102 establishments responded to 212 questionnaire forms sent out (for a collection rate of 48.1%).

- (1) The Support Centers for Developmental Disorders are places where users up to age 18 can seek advice.
 - 1) The assistance places emphasis on early diagnosis and early response in therapeutic education, normal education, medical treatment and other activities.
 - 2) Assistance to youth and adult users involves many things to consider in the future.
 - 3) For work supports, each establishment has been achieving results in collaboration with vocational rehabilitation establishments and various other establishments. Those efforts center on forming a bridge to specialized assistance establishments and acting as an intermediary.
- (2) The Support Centers for persons with disabilities at work and in their daily life, and support centers for the employment of persons with disabilities give personalized responses for employment to users aged 18 and older with developmental disabilities.
 - 1) The assistance places emphasis on personalized and concrete assistance until the person obtains a job.
 - 2) The centers collaborate with vocational rehabilitation establishments and various other establishments to achieve results in employing persons with disabilities.
 - 3) At some facilities, the system and collaboration are not ready in connection with diagnosing developmental disabilities.
- (3) Many users of support centers for persons with developmental disorders, support centers for persons with disabilities at work and in their daily life, and support centers for the employment of persons with disabilities suffer from pervasive development disorders in the category of autism regardless of whether having any intellectual disability.
Few users with learning or other developmental disabilities use these facilities.
- (4) Some specific supports require assistance spanning extremely long periods.

Regarding the response to youths "who cannot easily obtain a job due to their developmental disabilities" and those "who did not select assistance in vocational rehabilitation," it is hoped that assistance will be expanded through career guidance in educational establishments and through

consultation support at support centers for persons with developmental disabilities, along with other assistance. Conversely, some have obtained a job or become employed again through the collaboration of related establishments and development of assistance efforts. However, many big challenges remain to be addressed regarding the contents and period of assistance, such as what kind of assistance is effective and how much time should be allotted to fulfill an assistance target.

(2) Overview of the case survey

The survey covered 16 persons who gave responses and agreed to take a hearing in "A Field Survey of Youths and Adults with Developmental Disabilities at Work and in Their Daily Life," and who met the following requirements:

- 1) A finalized diagnosis such as autism, Asperger's syndrome or other pervasive developmental disorder has been made at a medical establishment for the person.
- 2) There is no intellectual disability.
- 3) The person must have a high school diploma or higher educational background and did not use vocational rehabilitation service in career selection at graduation.

In extracting the cases, we considered the present status (whether "employed," "unemployed" or "without a job"), and requested research cooperation in consideration of age and sex.

Based on findings from the questionnaire survey and hearing, we analyzed where the respondents went after graduation. An overview of the cases is as follows:

| Case | Age | Sex | Shift overview | | Current occupation | | | Disability certificate | | Basic disability benefit | | | |
|------|-----|--------|--------------------|-------------------------------|------------------------------------|--|--------------|------------------------|-----------------------|--------------------------|-----|-----------------------|-----|
| | | | | | Employment status | Whether disability was disclosed to the employer | Entry age | Acquisition age | Category | | | | |
| A | 40s | Female | Conventional shift | First job retained | General basis | Disclosed | 21 years old | No | | No | | | |
| B | 40s | Male | | | | Undisclosed | 18 years old | | | | | | |
| C | 40s | Male | Delayed shift | | Employed as person with disability | | 38 years old | 35 years old | Therapeutic education | Yes | | | |
| D | 20s | Male | | | | | 22 years old | 21 years old | Mental | | | | |
| E | 20s | Female | | | | | 25 years old | 25 years old | No | | | | |
| F | 40s | Male | Conventional shift | Many job changes | | Employed as person with disability | | 38 years old | 38 years old | Mental | Yes | | |
| G | 30s | Male | | Two job changes | | General basis | Disclosed | 30 years old | No | | No | | |
| H | 30s | Male | | Two job changes | | | Undisclosed | 23 years old | | | | | |
| I | 20s | Male | Conventional shift | Many job changes | | | | 23 years old | Mental | Yes | | | |
| J | 20s | Female | | | | | | 28 years old | | | | | |
| K | 40s | Male | Delayed shift | Left work once | | | | 35 years old | | | | Therapeutic education | |
| L | 40s | Male | | | | | | 35 years old | | | | Mental | |
| M | 30s | Male | Before the shift | Without vocational experience | | | | 21 years old | | | | Mental | Yes |
| N | 20s | Male | | | | | | 27 years old | | | | | |
| O | 20s | Female | | | | | | 25 years old | | | | | |
| P | 30s | Male | | | | | | No | | | | | |

Note 1: Conventional shift: By obtaining a job as a new graduate (through a common system in Japan helping students obtain a job upon graduating from school)

Note 2: Delayed shift: Not by obtaining a job as a new graduate (graduating with no job decision and then undergoing work training, using an assistance establishment or taking a similar course)

Note 3: Before the shift: Graduated from school but did not actively seek a job (remained at home or school, used an assistance establishment or pursued another activity with no job decision made, or for any other reason)

It has been made clear that, in order to effectively help a person obtain a job, it is important to evaluate their vocational aptitude, vocational interests and other traits when selecting a job according to objective standards instead of self-evaluation, and also appropriately assess the availability of assistance in vocational rehabilitation. When using vocational rehabilitation, people utilized various employment

supports (such as consultation, evaluation, training and vocational rehabilitation support), even when not eligible for the employment rate quota program.

One cause that makes people hesitate, avoid, postpone or become confused in selecting assistance is the issue of how people view their disabilities and persons with disabilities. Developmental disabilities other than cases with intellectual disabilities and mental disorders are not subject to the current employment rate quota of persons with disabilities. However, in the case of developmental disabilities diagnosed of people aged less than 18, there were people who changed in terms of status image with growth and obtained a job under the employment rate quota program for intellectual and mental disabilities.

These cases of employment are sometimes not regarded as successful cases, however, by persons with disabilities or their families (or they do not want to regard them as such). Moreover, the reason why the various names of disabilities (such as highly functional pervasive developmental disorders, highly functional autism, Asperger's syndrome and learning disabilities) are needed is closely related to the problem posed by the stigma of disabilities (particularly the stigma of intellectual disabilities). Providing barrier-free facilities for the disabled has long been a political challenge, but the most important challenge is to liberate the attitudes (barriers) of the people involved, the families concerned, and the persons with disabilities themselves.

While the notification of diagnosis typically leads the person concerned to select assistance, some have denied such notification. Even if this notification can help the person concerned accept the disability in question, the most important thing in actually proceeding with vocational rehabilitation was, whether in an actual workplace or a training scene simulating a workplace, to help persons with disabilities understand their own performance characteristics and clarify the requirements that must be considered, while learning the proper form of conduct required at the workplace. Moreover, in the characteristics of developmental disabilities, when a person must do something very novel (i.e., never experienced before), the person becomes uneasy and certainly confused, or finds it difficult to adapt to the change and assume the proper form of conduct. It has become clear that when considering these factors, along with other characteristics, it is necessary to secure a time and place for persons with disabilities in order to conduct sufficient exercises and confirmation that allow them to become comfortable not only in experiencing the actual workplace, but also in simulated training scenes. This means that assistance is needed for them in order to adapt to a given corporate culture. A corporate culture never experienced before and the presences of implicit rules in the workplace are the very things that bewilder and confuse these persons. Starting a new life in an actual workplace without such preparations requires an understanding that there are many people with extremely high levels of stress. In supporting persons with disabilities, it is therefore necessary to select a job according to an understanding of their characteristics, by controlling their problematic patterns of conduct, and helping them learn how to control their anxiety and stress according to an understanding of the corporate culture.

What is particularly at issue here would be: who should play the role of making proposals in vocational rehabilitation? To realize the gist of the Law for Assisting Persons with Disabilities, vocational rehabilitation is one role required of experts in educational assistance to promote a course of education appropriate for each individual. Regarding such a role, the concrete model would be the roles of course guidance representatives against the background of work assistance ideas at special-needs schools, and the mechanism of collaboration between educational and vocational rehabilitation. When any person with a disability has not yet selected and determined a shift to employment upon graduation, it is necessary to put the future use of vocational rehabilitation into perspective and provide assistance for promoting the shift from education to employment or from welfare to employment.

7. How to use the research findings

In addition to the fact that paving the way regarding developmental disabilities is still in the development stage, there are other circumstances, including the insufficient understanding of disabilities not only in the minds of persons with disabilities and their guardians, but also in corporations and society. The realities of employment status and other conditions of persons with developmental disabilities as revealed in this study can be used as information for education. This document will provide information not only for persons involved in vocational rehabilitation but also persons engaged in general education including special-needs educational personnel, along with persons related to work supports in communities. This survey report can be distributed to related establishments and the people concerned in order to provide information for consideration when providing vocational or course guidance.

There is a leaflet ("Work Support Guide for Employer and Youth with pervasive developmental disorders (Autism and Asperger's syndrome, etc.)" also provided. The leaflet will hopefully be used as information not only to educate employers but also to increase the availability of vocational rehabilitation for persons with disabilities, their families, and other people concerned.