

Original

INFLUENCE OF SOCIAL WELFARE REFORM ON SEVERELY DISABLED PERSONS

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Abstract

[Objectives] A new welfare policy for the disabled persons has been implemented in April, 2006 in Japan. It is aimed for achieving self-reliance where the disabled persons may be re-integrated into their communities. This research was conducted to understand its effects particularly on the severely disabled persons under institutional care and evaluate the validity of this policy.

[Methods] This research covered 320 severely disabled members of the welfare institutions. Data gathered were on severely disabled members before and after the policy implementation such as retirees, their economic and social conditions on health-related QOL using SF-8, as these were compared and evaluated.

[Results] From right before the implementation of the new policy in April until August, 25 out of 320 members (7.8%) left the institutions. Money that will be freed after deducting personal burden from the monthly income was averaging ¥61,900 before the implementation of (new) policy. It was expected to become ¥36,000/month after the implementation of a new policy, with an assumption that all 3 meals will be taken in the welfare institution. However, the actual "spare" money was ¥16,600 more than the calculated spare money, and it was identified that it was the result of having reduced the expenditure on meals to be taken in the institution, conserving transportation expenses and other daily commodities, and further limiting activities. It was also determined that anxiety over migrating from the welfare institution to the society was very prominent. Quality of life parameters such as physical functioning, general health, and mental health showed decline.

[Conclusions] The study indicated that the policy has negative effects than positive, causing limited activities and social participation, worsening functional disability, and even worsening health conditions. To achieve true self-reliance, they should be provided with real jobs with sufficient pay, and a liveable environment for all.

(JJOMT, 55 : 244—252, 2007)

—Key words—

Social welfare, Disabled persons, Deinstitutionalization

Introduction

Japanese social welfare program for person with disability has shifted from institutional service to home-based system since April 2006. In the former system, local municipalities decided the resource allocation for the person with disability. In the new system, government have started to provide monetary subsidies, allowing the person with disability to choose an institution of his/her preference, while the rest of the system remained unchanged. In April of 2006, a new law that contains self-reliance policy which was aimed at "building a society that allows the person with disability to be more self reliant and dwell in their respective community",

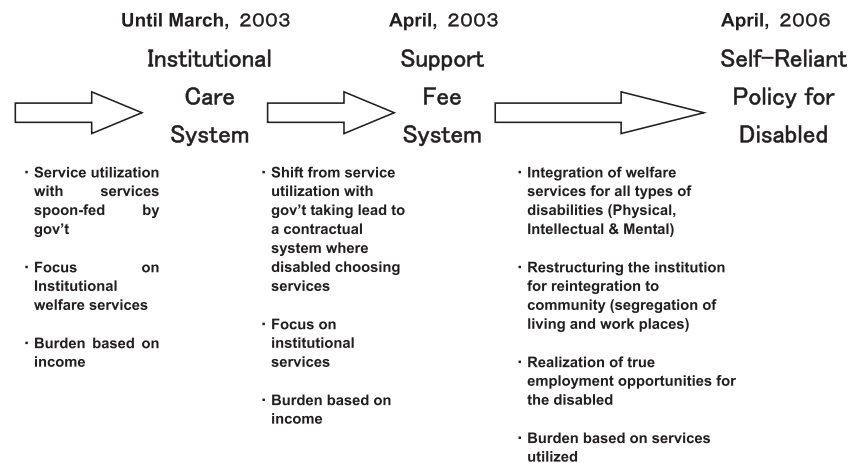


Fig. 1 SHIFT IN SOCIAL WELFARE POLICY FOR THE DISABLED

took effect.

New three policies apply to persons with severe disabilities who are currently residents of institutions. First, unlike the traditional policies which merely provided institutional services followed by a system of extending financial assistance whose amount depends upon the income, the new policy sets a financial support with fixed amount, with the personal burden on disabled persons depending on the utilization of the social services one avails, with no less than 10% of the applicable earnings. It is similar to the long-term nursing care insurance program for the aged¹⁾ (Fig. 1). Moreover, they are now obliged to shoulder 100% of the bills for meals taken in the institution as well as for utility/power. Secondly, in consideration of providing opportunity to the person with disability to become independent from the hands of the institution and to return to the community so that they can live a normal life like other people having no disabilities, the institutions should be restructured to segregate and the places for living and working should be made distinct. Thirdly, it is necessary to strengthen the support of the private sectors, particularly the corporations, to provide real job opportunities to the person with disability.

However, due to an abrupt change in the policy, we assumed that the financial burden on the severely disabled persons who are relying on the institutions would have significantly increased, and consequently forced them to limit the utilization of these services (leaving the institution, minimizing meal consumption, etc.) as a result of a decrease in loose money, they are limiting themselves to engage in hobbies and sports, and an aggravating anxiety towards non-assurance for securing a safe place for living.

In addition, what used to be paid to them as "wages" for the works they have rendered in the job/skills training centre, now goes to paying for meals and power, and it could be leading to demoralization towards work. Indeed, the implementation of the new policy have caused the person with disability, their families and the welfare institutions to experience much burden, and they are airing their grievances against the policy makers to review and change the policy. Institutions which are to implement the policy, are also left to much confusion, disappointment and grief.

The researchers thus conducted a preliminary investigation in order to evaluate the effect of this institutional reform²⁾. Unfortunately, its coverage was limited, and the validity of the conclusions derived from the findings was questionable. The authors have therefore conducted this research.

Materials and Methods

Objective

The objective of this study is to identify the changes in the daily lives of the severely disabled people who used to be a part of a welfare institution, but have returned to their communities as a result of a new, self-reliance policy, and to determine effects and applicability of the new law as well as identify any anticipated problems.

Coverage

320 severely disabled members of either of the two welfare institutions operating in Beppu City as of March, 2006 (255 males, 65 females, and ages ranging from 19 to 71, with an average age of 42.3 years old). They have been in the institution for a period ranging from 11 months to 37 years and 6 months, with an average of 12 years and 8 months. There were 15 married people (4.7%), and of these, 2 couples were staying in the institutions together.

Procedure

I. Withdrawals: Compared the number of member-residents who left the institutions, and the reason for leaving the institutions, as well as their living conditions outside of the institutions in March, 2006, before the implementation of the new policy, and in the end of August, after the implementation.

II. Changes in the cash flow of the trainee-members of the institution: Compared the actual earnings and expenses of the trainee-members of the institution before the implementation of the new policy in March 2006; and after implementation, in June of the same year.

III. Changes in the daily activities of the trainee-members of the institution: to understand its effect on the social participation and shift from institution to "regular" activities outside of the institution, case workers conducted interviews and questionnaire surveys among 160 trainee-members who have given their consent, before (March) and after (August) the policy implementation.

IV. Changes in the QOL (Quality Of Life) related to Health: Caseworkers of the respective institutions measured and evaluated using SF-8³⁾, changes in QOL of 214 consenting trainee-members before (March) and after (August) the implementation of new policy. SF-8 is a tool to measure and evaluate the health condition of a person. For its comprehensive coverage, it is widely used in medical service researches and outcome studies among others. 3 of the 8 categories of measure, such as Physical Functioning, General Health, and Mental Health, showed significant changes, and the rest are daily-role functionality (physical), body pain, vitality, social functions, daily role functionality (mental), and emotional health.

Results

I. Leaving the welfare institutions

By the end of March 2006, right before the implementation of the policy, there were 14 out of 320 (4.4%) who decided to leave the welfare institutions. After the policy implementation, 6 left by the end of April, 2 in May, 1 in June, 1 in July, and 1 in August, making the total number of withdrawals from the welfare institutions from March to August, 2006 twenty five (25) out of 320 (7.8%). The destinations of the retirees/those who left were: to his/her own residence to join the members of the family, 16; transferred to another welfare institution, 4; and those who found employment, 5.

II. Changes in income and expenses as a result of changes in policy

(1) Income

There is no factor affecting the income as a result of change in the policy, as the income before and after the implementation did not change. For the severely disabled people, their monthly income varies depending upon the labour wages they earn from the job training centre. The labour wage averages 20,000 yen per month. Thus, similar to the situation prior to the implementation of the policy, their income varies depending upon the kind of pension they are entitled to receive from the government. In addition to this, there is rehabilitation training allowance ranging from 1,600 yen to 6,300 yen a month, the amount of which depends upon the community they belong, depending on the degree of disability, and the level of earnings. Therefore, before and after the new policy implementation, the major factor involved is whether one is entitled to receive such pension and allowances from government or not. The average of the income was approximately 83,100 yen a month (there was actually a decrease of 1,000 yen per month before and after the implementation of the policy. However, this is due to a decrease in labour wage itself, and is not because of the policy change). However, for the ones who are entitled to pension (including livelihood protection allowance), the average of monthly income was 97,400 yen, while it was approximately 23,800 yen for those who did not receive any pension (Table 1).

(2) Increase in personal burden after the implementation

Due to the implementation of the new policy to shoulder at least 10% of the service utilization fee, and to pay out of one's "own pocket" for meals and utility (power, gas, and water) fees, consequently the sum of these appears as an increase in expenditures after the implementation of the new policy. While there are several reducing measures to minimize the impact of an increase in service utilization fees depending on the income, the average of the expense was still 7,200 yen a month. The personal burden for meals and utilities between the two institutions has only slight difference, and basically it is estimated to cost 1,500 yen per day or about 45,000 yen per month, if three meals were taken at the institutions. For utility, personal burden is fixed at 5,000 yen a month. Based on a survey done after the implementation of the new policy in June, however, the actual outlay averaged at 30,600 yen. For pensioner, it was 35,400 yen while it was 9,000 yen for non-pensioner, which was lower than it was expected. The reason for the lower amount may be due to a decrease in expenditures for meals, which is controllable by each person (Table 1).

(3) Changes in the take-home-money (anticipated and actual)

The net take home money free for use by each person would decrease as a result of the implementation of new policy, because there was no increase in the income while expenditure or personal burden increased. When supposing three meals were taken at the institution, the net take home money would average at 36,000 yen (pensioner averaging at 44,000 yen and non-pensioner at 5,800 yen). However, since the actual disbursement was lower than expected ; they actually received more than our assumption, 15,600 yen more (17,400 yen more for pensioners and 9,200 yen more for non-pensioners) (Table 2).

III. Effects on the daily living as a result of change in policy (per questionnaire survey results)

(1) Meals :

For a question of whether one is taking meals everyday in the institution's cafeteria, those who answered "taking meals properly" at the institution decreased from 58.0% to 56.7% for breakfast, 67.1% to 55.6% for lunch, and from 62.1% to 52.2% for supper, while those who merely take meals at the institution increased from 16.8% to 21.3% for breakfast, 6.2% to 10.6% for lunch, and 7.1% to 15.9% for supper (Table 3).

(2) Impacts as a result of a decrease in net take home money :

For a question, "Where do you try to save money on?" (147 respondents before and 154 respondents after the implementation of the new policy), those who answered in Transportation fees for bus, JR train and taxi fares shifted from 18.9% to 22.1%, for Daily Goods (such as toiletries and cosmetics) from 7.6% to 13.6%, and in savings from 4.5% to 5.2%, and they were subject to cost-cutting measures. On the other hand, Hobbies/Leisure (such as movies, music, games, purchase and rental of CD, etc.) shifted from 10.6% to 9.7%, Meals (foods & beverages, including dining out and drinking liq-

Table 1 Changes in income after policy implementation, n=284

	Pre-Implementation (month ave.)		
	Over-All	With Pension	Without Pension
Income	83,100	97,400	23,800
Burden	21,300	25,800	1,100
	Post-Implementation (month ave.)		
	Over-All	With Pension	Without Pension
Income	82,100	96,300	23,500
Burden	30,600	35,400	9,000

Table 2 Changes in the free money after policy implementation, n = 284

	Pre-Implementation (month ave.)	Post-Implementation (month ave.)	
	Spare Money	Estimated Spare Money After 3 Meals at the Inst.	Actual Spare Money
Over-All	61,800	36,000	51,600
With Pension (n = 232)	70,500	44,000	61,400
Without Pension (n = 52)	23,000	5,800	15,000

Table 3 Taking Meals

< Over-All >	(1) Breakfast			(2) Lunch			(3) Supper		
	March	August	%Change	March	August	%Change	March	August	%Change
	n = 143	n = 136		n = 146	n = 142		n = 140	n = 138	
Always Eating	58.0%	56.7%	- 2.2%	67.1%	55.6%	- 17.1%	62.1%	52.2%	- 15.9%
Sometimes Not	25.2%	20.6%	- 18.3%	26.7%	33.8%	26.6%	30.7%	31.9%	3.9%
Almost Not	16.8%	21.3%	26.8%	6.2%	10.6%	71.0%	7.1%	15.9%	124.0%

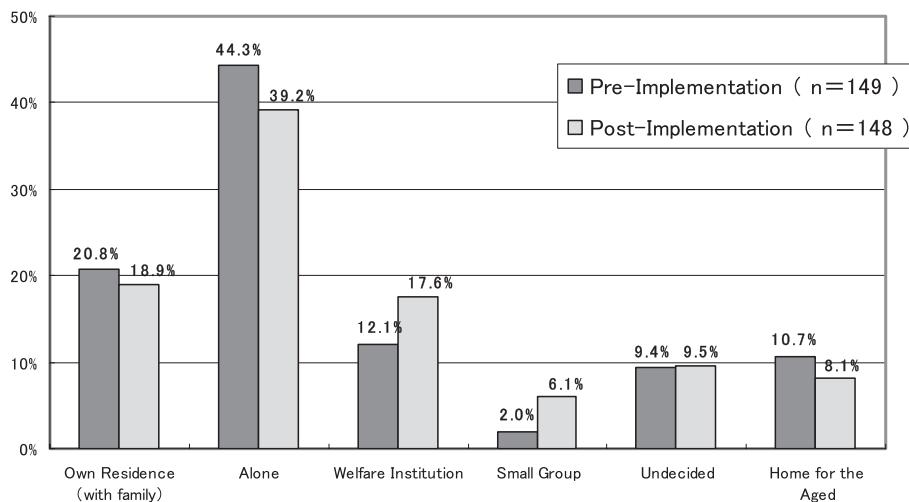


Fig. 2 Preferred living condition

uor, etc.), from 28.0% to 25.3% ,for use of mobile phone from 12.1% to 9.7%, for gambling (e.g. pachinko, cycling race) from 16.7% to 13.6%, and for sports activities from 1.2% to 0.6%, showing that these were not subject to saving efforts as a result of tighter budget. Those who answered others increased from 4.5% to 5.2%.

(3) Activities :

On a question regarding frequencies for participating or engaging in hobbies, gambling (pachinko, cycling race), sports and cultural activities, there were 160 respondents before and after the policy implementation (multiple answers possible). Among those who engaged in those activities more than once a month, hobbies decreased from 74.0% to 70.5% ; gambling from 21.2% to 18.5% ; while sports & cultural activities increased from 13.7% to 17.8%.

(4) Response to the policy for moving out of the institution for community integration

(4)-1 For a question of “How/What kind of place would you like to live in?” (149 respondents before and 148 respondents after), those who said “live alone” showed decrease from 44.3% to 39.2% ; “at own residence (together with families and relatives)” from 20.8% to 18.9% ; “in homes for the aged” showed decrease from 10.7% to 8.1% ; while showing increase for those who said “in group (small numbers of people)” from 2.0% to 6.1%. Also, for those who wished to join welfare institution (for the person with disability) increased from 12.1% to 17.6%, contrary to the objective of the new policy (Fig. 2).

(4)-2 Anxiety towards living on his/her own : “What would be your main concern if you are to live on your own outside of the institution?” (160 respondents before and after), The answer “Health” shifted from 22.5% to 25.0% ; meals from 20.6% to 18.8% ; the living expenses showed increase from 19.4% to 24.4%, managing/budgeting finances from 10.0% to 15.6%, means of transportation/moving from 1.3% to 6.3%, house chores from 3.1% to 12.5%, nursing/care-giving from 4.4% to 7.5%, moving within and outside from 3.1% to 5.6%, social interaction from 0.0% to 4.4%, and housekeeping/maintenance from 7.2% to 8.8%. Except for meals, every item showed significant increases in their worries.

(5) Reaction towards job promotion policy : For a question of “Would you like to continue to get a training

(work) in the institution? (141 respondents before and 136 respondents after), 86.5% answered yes before the implementation of the policy and 86.8% after the implementation. For one's objective for staying in the institution, there were 146 respondents before and after (multiple answers possible). Those who aimed for job training decreased from 57.5% to 54.1%, comprising more than a half of the respondents. It was followed by those who answered "for earning income (labour wage)", which decreased from 42.5% to 39.7%. For establishing social skills" decreased from 23.3% to 17.8%. "As a place to live" decreased from 37.2% to 32.2%. "Preparation for employment" decreased from 20.5% to 17.8%. "For maintaining and improving physical skills (skills training)" decreased from 32.9% to 31.5%. For joining group activities decreased from 11.0% to 10.3%. "Has no objective" increased from 1.4% to 2.7%.

IV. Changes in health-related QOL

When surveyed 214 respondents both before and after the implementation of the new policy, it was significantly lower than the national average level (based on SF-8 conducted among 1,000 residents of Japan, with age ranging from 18 to 75 years old) in all 8 categories, reaching risk level 5%. When results are compared before and after the implementation of this policy, 3 out of 8 categories including Physical functioning, General health, and Mental health showed significant decrease, while the rest, i.e., Role physical, Body pain, Vitality, Social functions, and Role emotional showed no changes before and after the implementation (risk level of 5%).

Discussion

Due to the implementation of the new policy, the following results were anticipated among the severely disabled residents of the welfare institutions: (A) Limiting the use of the institutional services, (B) less activity, (C) fear and anxiety among the residents increasing significantly when discharged from the institutions, and (D) less motivation towards work.

A) Decrease in the use of the welfare services.

In the survey conducted among 1,984 members of the welfare institutions and job training centres for the physically disabled people, by "Total Self Cooperative" in April of 2006 after the implementation of the self-reliance policy, there were 60 members who had left the institutions (3.02%) due to an increase in the financial burden, and there were 92 members (4.64%) who planned to leave the institution sometime after April, with the same reason. In this study, the discharge rate by the end of March was 4.38%, and 7.81% from April until August, both showing high rates compared to the national average⁴. Even if excluding five members who left the institution due to employment, the rate was 6.25% (20 out of 320 members). Also, this study indicated that they tried to minimize expenditures on meals taken inside the institutions. The respondents of this study who are severely disabled and have been in the institutions were relying on the welfare services provided to meet basic necessity to lead a normal life, such as taking a bath, eating, going to the toilette, etc., and it is not for them to take advantage of the support available. If the policy is such that the financial burden will depend upon the services utilized, the severely disabled persons who are indeed in need of these services will have to shoulder more burdens, as a result of needing more services. Even the supermarkets nearby those two welfare institutions covered by this study reported that their sales for cheaper packed meals, instant/pre-cooked meals, and rice for those who opt to prepare and cook their own meals have increased after the implementation of the new policy. Some may oppose to this, and bring up the issue of nursing care insurance for the aged, where it makes it compulsory for one to shoulder 10% of the social services fee. But in the case of severely disabled people, it must be noted that there was no period in their life when one was able to work and earn like the able person, hence they earn low income throughout their lives, thus making it difficult for them to save. This fact makes them apart from the situation of the senior citizens as covered by the nursing care insurance for the aged. As the objective of the new policy is "to build a society where the person with disability can lead as normal life as possible", then a truly meaningful and useful welfare services must be guaranteed by the government, without passing the burden on the person with disability themselves.

B) Less activity.

The questionnaire survey revealed that expenditure for outing and for other daily needs were being cut, as saving money was becoming even more difficult. From the SF-8 conducted on the health-related QOL, it

was also determined that Physical functioning, General health, and mental health were degraded. It is feared that changes in lifestyle brought about by the implementation of new policy eventually lowers the level of activities, resulting to inhibition from participating in social activities, worsening the functional disorder, and even negatively affecting the life of the person with disability in general⁵. While the expenditure for dining/drinking out, toll for using mobile phones and gambling, as well as for engaging in sports activities were not controlled/limited by the implementation of the policy, these may be considered to be the more important aspects in life, and they would want to keep them, even in exchange for sacrificing on meals.

C) Anxiety caused by the non-guarantee of the place for living.

The administration says the implementation is to take full effect in 5 years (Heisei Year 23) or by the end of 2011, to discharge the severely disabled people from the institution for their re-integration to the society. As a result of the questionnaire survey conducted, the anxieties of the respondents towards integration are ranked in the order of: one of the basic human needs: meals; living expenses, financial management and other economic issues. Economic issues which will be brought about by leaving the institution and living outside included means of moving indoor and outdoor, means of transportation and commuting to work. Health, social interaction, performing house chores, nursing/care-giving, all showed increased anxiety after the implementation of the new policy. Also, on the condition for living, while those who opt to live on his/her own alone decreased from 44.9% to 38.3% by 11.6 percent; those who opted to join/remain in the institution increased from 12.5% to 18.4% by 5.9 percent; and who opted to live with a small group increased from 2.2% to 6.4% by 4.2 percent. For the place to live, those who prefer their hometown decreased from 54.3% to 47.5%; where their family members and relatives are decreased from 13.3% to 7.5%, while those who want to stay near the institution increased from 32.4% to 45.0%. These changes may be exhibiting their worries for moving to a place where environment (system or infrastructures) is not suitable for disabled persons. The earnings of these disabled persons are 97,400 yen a month for pensioner and 23,800 yen for non-pensioner, thus it is difficult for them to find an apartment and pay for the rent. The problem is not only rent, but the fact there must be sufficient home-help to look after their health condition and meals, barrier-free infrastructures where the disabled can commute between work place and home with ease safely, a community that does not discriminate the person with disability, and an environment which makes it possible to achieve the objective of re-integration of the person with disability to its society for them to live outside of the institution. However, these are still not readily present.

D) Less motivation towards work.

It was feared that they will have less motivation toward work, because the implementation of the new policy made them pay the institution for their meals and utility, despite of working in the welfare institution's job training centers to earn income. However, the result of the survey showed that as much as 86% (same before and after the new policy implementation) showed interest in keeping their job (training), and that they are eager to work and to be employed. The new policy indeed declared to build a society where there were more jobs for the person with disability, and the administration had set its target to secure 600,000 employment for the person with disability in 2 years (2008)⁶ and next fiscal year's financial requirement for this is said to be 14,752,000,000 yen (an increase from initial budget for fiscal Year 18 of Heisei (2006-2007) by 982,000,000 yen (increase of 7.1%)⁷). However, the attainment rate of employment based on the person with disability work promotion policy of 1960 is still 1.49% at this moment, and the compulsory rate of 1.8% has never been attained. 58% of the corporations in fact do not satisfy this requirement⁸. The employment rate of the person with disability are computed such that for those who are severely disabled and qualify for both level 1 & 2 disabilities based on their card, count as two, even if in fact, it is only one person with 2 levels of disability. It is so-called double count). But the actual employment for the person with disability is only 190,000, even after a half a century since the 1960. Yet this is covering all disabled persons, and for the severely-disabled, the chances of getting employed are tremendously low due to them having less occupational capability. In Europe and the United States, the administrations have started to work on providing employment to the person with disability with jobs that pay the same level of salary/wages to that of able persons⁹. Thus, we hope that a true employment opportunity, and not just an internship, or job training in welfare institutions, be available to the severely

disabled people in Japan, at the onset of the implementation of this new policy.

Conclusions

As citizens of Japan, even the severely disabled persons should be respected like the rest of the citizens. Their basic necessity such as food, clothing and shelter must be guaranteed by the government. For the person with disability to be truly self-reliant and for discharging of these people from their institutions to be realized, there must be true employment opportunities, not only training centers or institutions which gives them only meagre allowances, but where equally meaningful earnings are provided so that they are considered not as disabled persons to be a burden to our society, but as workers. The disparity among all citizen, including so-called disabled people, should be eliminated by the government in settling policies, and implementing guidelines.

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障害者自立支援法の重度障害者への影響

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—キーワード—

社会福祉, 障害者, 脱施設化

〔目的〕

2006年4月に施行された障害者自立支援法により脱施設化地域移行の対象となった施設利用重度身体障害者の生活全般にどのような変化が生じているかを明らかにし、この法律の有効性と課題を検証することを目的に調査研究を行った。

〔対象〕

新法施行直前の2006年3月において、別府市に2カ所存在する入所授産施設の重度身体障害者320名、(男性255名、女性65名、年齢19歳～71歳、平均年齢42.3歳)を対象とした。

〔方法〕

法施行前後の退所者数、収支状況、生活状況、健康関連QOL(SF-8^①)について調査し、比較検討した。

〔結果〕

法施行直前の3月末から8月末までに320名中25名(7.8%)が退所した。法施行前の月収から負担金を引いた自由になる金額は、月平均61,900円であった。施行後、

食事を3食とも施設で摂ったと仮定した場合の月収から負担金を引いた自由になる金額は、月平均36,000円に減少すると推定された。しかし、実際には、推定より16,600円多く、その理由として、施設に支払う食費を削り、外出の際の交通費・日用品を節約、さらには活動を制限して自由になるお金を捻出したことが明らかになった。また施設から地域生活移行への不安も顕著であることがわかった。SF-8の調査では、8項目中Physical functioning, General health, Mental healthの3項目において施行後に有意に低下していた(危険率5%)。

〔結語〕

新法施行により、活動低下、社会参加の抑制、機能障害の悪化、さらには健康状態まで、重度身体障害者の生活全般に悪影響を及ぼすことが危惧される。自立のために、施設解体地域移行を推進していくには、授産という低所得での就業ではなく、一般と同等の所得での就業と、地域生活を可能とするための社会環境作りが不可欠である。