Current Status of the Adult Guardianship System in Aomori Prefecture

:Focusing on Types of Social Welfare Service Providers and their Users

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Abstract The purpose of this study was to clarify the current status of the Adult Guardianship System (AGS) in 32 municipalities in Aomori prefecture. This involved estimating the number of social welfare service users who were entitled to use the AGS, clarifying which types of social welfare service providers had more users who needed the AGS, and capturing the social welfare service providers' perceptions of the AGS.

This was a cross-sectional survey. We sent questionnaires to 2,477 providers. Of the 2,477 providers, 1,094 of them (44.2%) returned completed questionnaires.

The results indicated that many users were entitled to the AGS, but they did not use the AGS. These providers recognized that the AGS was essential for users, but they were not sure how to access the AGS. The results of comparison of providers for the elderly and providers for users with disabilities showed that in the near future providers for users with disabilities would need more information about the AGS, compared with providers for the elderly. One of the reasons of the survey results seemed to be related with problem of aging parents of the users with disabilities.

Receiving consultations about the AGS from legal experts and municipalities is useful for social welfare service providers. In joint council, social welfare service providers play an important role to encourage users to participate in the decision-making process. Social welfare service providers are experts of supporting the users' decision making.

Introduction

This study reports on a survey conducted in 2018 in Aomori area (see below for further details), Japan. The Aomori Bar Association and the Tohoku Federation of Bar Associations were responsible for organizing the survey. The survey was designed to determine the number of

elderly people or people with disabilities who were entitled to the Adult Guardianship System (AGS).

We selected 2,477 social welfare service providers as a sample group. We sent questionnaires to the managers to complete, and 1,094 providers (44.2%) returned the completed questionnaires, providing information on 7,013 users who had impaired decision-making capacities due to mental disabilities, intellectual disabilities, or dementia.

A large gap was observed between the estimate based on the survey results (7,013) and the

Kenya ISHIDA Takayuki KASAI 青森県立保健大学健康科学部 1) Aomori University of Health and Welfare actual number recorded in the documents for Aomori prefecture (323)¹⁾. This indicated that most users who were entitled to use the AGS were not using the AGS.

We analyzed the survey results in depth with an instrument of cross tabulation by types of the providers. The results showed that the providers for users with disabilities would need information about the AGS, compared with the providers for the elderly in the near future. At this point in time, many providers for users with disabilities had little experience of introducing users to the AGS, compared with the providers for the elderly.

It should be reformed to make it more userfriendly and facilitate cooperation between the providers, lawyers and municipalities, and to ensure they work together as a team. Receiving consultations about the AGS from legal experts and municipalities is useful for social welfare service providers. Social welfare service providers play an important role to encourage users to participate in the decision-making process.

Background of the survey

The AGS was introduced in Japan as part of the reform of the Civil Code in 2000. From 2000 to 2016, the number of people using the AGS had increased more than three times (from 9,000 to 30,079)^{2) 3)}. Under the "Law Related to the Mental Health and Welfare of Persons with Mental Disorders," the "Law of the Welfare of Persons with Intellectual Disorders," and the "Law of the Welfare of Elderly Persons," the mayor of a municipality can petition assessments of people who are in need of the AGS and have no support from relatives.

The number of cases that the municipality mayor petitioned increased by 300 times in the

same terms (from 23 in 2000 to 6,466 in 2016) ^{2) 3)}. The number of cases that a municipality mayor petitioned tended to increase year by year steadily.

In Tohoku area, aging rate and prevalence rate of dementia increase rapidly and steadily, on the other hand, rate of using the AGS is not increasing, so municipalities must take the initiative for promoting the use of the AGS⁴). In Aomori prefecture, the number of petitions in the AGS was 323, and 119 out of 323 were cases that a municipality mayor petitioned (36.8%)⁵).

In 2016, the Hachinohe Adult Guardian Center conducted a survey to investigate the actual conditions of the users of the long-term care insurance service, or social welfare services for people with disabilities in the Hachinohe area (eight municipalities), in order to estimate the number of people who should be able to use the AGS. The survey results showed that at least 1,000 users were potentially in need of the AGS, one-quarter of them didn't have relatives who could provide care for them, and one-quarter had financial problems⁶⁾.

In 2013, the Social Welfare Council of Niigata Prefecture conducted a survey to determine the potential number of social welfare service users in need of the AGS. They found 5,653 users needed the AGS in Niigata prefecture, and 1,229 of 5,653 users needed professional guardianship⁷⁾.

In 2015, the Social Welfare Council of Shizuoka Prefecture conducted a survey to determine the potential number of social welfare service users in need of the AGS. The survey results showed that 22,427 users needed advocacy services such as the AGS in Shizuoka prefecture⁸⁾.

In 2011, the Ishida team conducted a survey to determine the potential number of elderly people who might be eligible for the "Support Program to Use the Adult Guardian System for Persons with Disabilities", and they found

that 1,771 users out of 5,302 in Aomori city had impaired decision-making capacities due to mental disabilities, and about 4,000 elderly users in Aomori city might use the system in the future⁹⁾.

Several surveys have been conducted on the need for the AGS in Japan over recent years, and researchers have clarified that there were many users who were entitled to use the AGS but did not. Some of the results of these surveys were reflected in measures to promote the AGS.

Only a few attempts have been made so far to conduct surveys on the AGS in prefectural level. In Aomori prefecture, a survey ascertaining the need for the AGS was not conducted at prefectural level, only in Hachinohe city and Aomori city. These were sporadic rather than systematic.

We thought we should conduct the survey on the need for the AGS in Aomori prefecture to estimate the potential number of users who were entitled to use the AGS and to capture the full picture of welfare service providers' perceptions of the AGS in Aomori area.

Methods

This was a cross-sectional survey. We sent questionnaires to 2,477 social welfare service providers and psychiatric hospitals in Aomori prefecture, which included institutions for the elderly, Community General Support Centers, institutions for people with disabilities, Councils of Social Welfare where they offer the independent living support program, and psychiatric hospitals. The survey was conducted by the Aomori Bar Association and the Tohoku Federation of Bar Associations initiatives.

We conducted the survey in Aomori area. There were 40 municipalities in Aomori prefecture, and 32 municipalities were selected as a sample (referred to as Aomori area). Hachinohe

area (eight municipalities) was excluded, as the survey in 2016 had been already done^{6) *)}.

Of the 2,477 providers, 1,094 social welfare service providers (44.2%) returned completed questionnaires. The information obtained by the survey covered approximately 7,013 users. We asked the providers about the users they supported. The survey questionnaire included five items as follows.

- No.1 The number of the users who had impaired decision-making capacities due to mental disabilities/ intellectual disabilities/ dementia.
- No.2 Among the users who were counted in No.1, the number of users who endured daily life difficulties, such as consumer damage, inadequate property management, and economic abuse.
- No.3 Among the users who were counted in No.2, the number of users who prepared for the use of the AGS on the occasion of the survey.
- No.4 In case of No.4, what prevented users from using the AGS.
- No.5 For the providers who had no users with impaired decision-making capacities, the number of users who would use the AGS in the near future.

In the case of No.1, we asked the providers to provide information where applicable. Detailed information about the users included the following: daily life difficulties, age, diseases or disabilities, income, and the presence of relatives.

We also asked them to provide the number of users preparing for the use of the AGS, and what prevented the users from using the AGS. If they answered that they didn't have any users who needed the AGS on the occasion of the survey, we asked them to provide the number of users who would be likely to use the AGS in the near future

After checking, all returned questionnaires were deemed valid and the data was analyzed. The data were subjected to statistical analyses using SPSS ver. 24.0 software and Microsoft Excel 2019.

We sorted users' data by types of the providers (providers for the elderly (437) and providers for people with disabilities (241)) and analyzed the data to clarify which types of the providers had more users who needed the AGS. One point to make sure here was that the providers for users with disabilities accommodated users regardless of age, so users with disabilities included those over 65 years old.

We also conducted cross tabulation by types of the providers. We calculated the rates of the providers for users with need of the AGS on the occasion of the survey and in the near future, and then compared the rates.

Ethical consideration

The Aomori Bar Association and the Tohoku Federation of Bar Associations were responsible for organizing the survey. The questionnaires clearly stated the following: the questionnaires were anonymous, so privacy was protected; cooperation was voluntary, and the results would only be used for academic purposes and to improve the promotion of the AGS.

Results

The Situations of the Social Welfare Services Users

Demographic characteristics were shown in four Tables (from table 1–1 to table 1–4). The data indicated that 7,013 users had impaired decision-making capacities due to mental disabilities/intellectual disabilities/ dementia (Table 1–1).

Age was ranked over ten levels. The largest group were in their "80s" (32.5%, 1,876 users), the

Table 1-1 The number of the users who had impaired decision-making capacities due to mental disabilities/ intellectual disabilities/ dementia.

		N
legal acts	The user has an experience of suffering from consumer damage (or being harassed by dishonest dealers).	141
	The user can only manage daily expenses, but not legal acts such as sales of real estate or agreements on the division of an inheritance.	2,682
	The user can't understand legal matters such medical examination contracts and welfare service contracts.	1,903
property management	The user cannot manage real estate due to his/her incapacity.	205
	The user can't manage their finances such as payments of his/her taxes and payments for the institutions.	200
	The user buys expensive items beyond his/her income.	394
abusive treatment	The user is or may be suffering from financial abuse (e.g., exploitations of his/her pension and bank deposits).	206
	The user is or may be suffering from physical abuse, mental abuse, sexual abuse, and neglect.	95
	The user denies receiving necessary medical/care/social welfare services.	243
Others	The user can't manage other activities of daily life.	944
Total		7,013

N=the number of the users

second largest in their "60s" (13.4%, 776 users) and the third in their "70s" (13.3%, 771 users) (Table 1-2).

The main disability/disease was "dementia" (50.1%, 2,772 users), followed by "intellectual disability" (22.9%, 1,266 users), "mental disability" (15.1%, 835 users), and finally, "developmental disability" (4.3%, 239 users) (Table 1-3).

After analyzing and processing the data, a large gap was observed between the estimate based upon the survey results (7,013) and the actual numbers recorded in the documents for Aomori prefecture in 2017 (323).

The total number of users who were preparing for the AGS on the occasion of the survey was 359, and the total number of users who would need the AGS in the near future was 958 (Table 1-4).

Table 1-2 The number of users by age

Age	N
under 19 years old	38
20s	314
30s	358
40s	425
50s	444
60s	776
70s	771
80s	1,876
90s	736
over 100 years old	39
Total	5,777

N =the number of the users

(2) The Situations of the Social Welfare Service Providers

The social welfare service providers were sorted into two types, one for users with disabilities (241 providers) and the other for the elderly (437 providers). 70 providers were excluded because their type of services was unknown.

The total number of elderly users with need of the AGS at the occasion of the survey (122) was larger than the total number of users with disabilities (86). In the near future, this will reverse, at 155 and 453 respectively (Table 2).

The results of cross tabulation by types of the providers were shown in table 3-1 and table 3-2. On the occasion of the survey, the number of the providers for elderly was 77 (17.5%), and that of the providers for users with disabilities was 35 (14.5%). The odds ratio was 1.26 (95 percent confidence interval, 0.82 to 1.84). On the other hand, as for in the near future, the number of the providers for the elderly was 78 (34.1%),

Table 1-3 The number of users by disease / disability

Disease / Disability	N
dementia (or suspected)	2,772
intellectual disability (or suspected)	1,266
mental disability (or suspected)	835
developmental disability (or suspected)	239
Others	419
Total	5,531

N= the number of the users

Table 1-4 The total number of users who have possibilities for using the AGS

	cases
the total number of users who would need the AGS in the near future	359
The total number of users who were preparing the use of the AGS at the occasion of the survey	958

N =the number of the users

Table 2-1 Comparison between the number of the elderly and that of users with disabilities

	providers for the elderly users (N=437)	providers for users with disabilities (N = 241)
the total number of users who would need the AGS in the near future	122	86
The total number of users who were preparing the use of the AGS at the occasion of the survey.	155	453

N=the number of the providers

Table 3-1 The number of the providers who have users preparing the AGS at the occasion of the survey

	for the elderly users	%	for users with disabilities	%	total
applicable	77	17.6	35	14.5	112
no applicable	360	82.4	206	85.5	566
	437		241		678

Table 3-2 The number of the providers who have users with using the AGS in the near future

	for the elderly users	%	for users with disabilities	%	total
applicable	78	34.1	69	58.0	147
no applicable	151	65.9	50	42.0	201
	229		119		348

and that of the providers for users with disabilities was 69 (58.0%). The odds ratio was 0.37 (95 percent confidence interval, 0.23 to 0.59).

Discussions

The results showed that many users were entitled to the AGS, but they did not use the AGS. This finding is consistent with previous surveies⁶⁾⁻⁹⁾.

In this situation, it will be useful for social welfare service providers to receive consultations about the AGS from legal experts and municipalities, as stated the Law of Promoting Use of the Adult Guardianship System. Joint council where social welfare service providers, lawyer associations and municipalities can meet is very important for advocating users of social welfare service

providers. Joint councils will facilitate cooperation between social welfare service providers, lawyers, and municipalities and ensure they work together as a team. Lawyers should advise or supervise welfare service providers more actively to ensure that the providers comply with the law. Municipalities have the responsibility for holding joint councils with social welfare service providers and lawyers, and for coordinating the efforts of city hall, the family court, lawyers associations, social welfare organizations, and medical institutions. Municipalities have also a responsibility to develop a budget for promoting the AGS. This will also provide opportunities for welfare service providers to obtain information about the AGS and how to access the AGS. Social welfare service providers will then be prepared to assist service users with the cooperation of lawyers associations and municipalities.

Social welfare service providers should encourage their users to participate in the joint council for advocating their users10). Social welfare service providers have essential and necessary information of their users, e.g. their personalities, preferences, hope for their daily life. Social welfare service providers are experts of supporting the users' decision making. It has been pointed out that the AGS users must be guaranteed the right to self-decision making¹¹⁾. It has also pointed out that people with disabilities don't have information on the social welfare system and they also don't understand the system correctly¹²⁾. If their users have difficulties to communicate, social welfare service providers can put themselves in their users' shoes and advocate their users. Social welfare service providers should play an important role to encourage users to participate in the decision-making process¹³⁾.

This will also provide opportunities for welfare service providers to obtain information about the AGS and how to access the AGS. Social welfare service providers will then be prepared to assist service users with the cooperation of lawyers associations and municipalities.

The results of the cross tabulation by types of the providers also indicate that social welfare service providers for users with disabilities will need information about the AGS more than social welfare service providers for the elderly in the near future. At this point in time, many social welfare service providers for users with disabilities have little experience of introducing users to the AGS, compared with providers for the elderly.

There are about 220,000 people who use the AGS all over Japan in 2019. Those who are 65 years old or older account for about 71.8% of all males, and it accounts for about 86.0% of all women¹⁴⁾. In the current situation, most of the AGS users are elderly. In this survey, a total number of elderly users with need of the AGS at the occasion of the survey is larger than that of users with disabilities. The result of this survey seems to be consistent with the report¹³⁾.

We also find that, in the near future, the number of users with need of the AGS will reverse. There are some reasons why the number of users with disabilities will increase more than elderly users. It has been pointed out that one of the reasons why the users with disabilities must use the AGS is by aging their parents¹⁵⁾. The result of this study indicates that about 40% of 7,013 users has disabilities, 20% of them has "intellectual disability", about 15% of them has "mental disability" and about 5% of them has "developmental disability". When parents of users with disabilities can't take care of them by aging, some of the users with disabilities use the AGS. It has been pointed out that we use the AGS actively for advocating their human rights, considering the disability characteristics¹⁶⁾.

Social welfare service providers have the primary responsibility for caring, advocating, and supporting the users' family. In this study, 7,013 users from Aomori area had impaired decision-making capacities due to mental disabilities, intellectual disabilities, or dementia, However, the actual number recorded in the documents for the Aomori area is 323. It means that there is a large gap between the estimated number based on the survey results and the actual number. This indicates that many users are not using the AGS and social welfare service providers are increasingly expected to introduce users to the AGS in the near future.

The participation of lawyers will be a great help to users, their families, and welfare service providers. Lawyers can advise or supervise social welfare service providers more actively to ensure they are complying with the law. The users and their families would have an opportunity to solve their legal problems thanks to the lawyers.

Social welfare service providers should encourage their users to be a member of the joint council, and have essential and necessary information of their users. Social welfare service providers are experts of supporting the users' decision making. It means that social welfare service providers play an important role to participate in the decision-making process.

There are some limitations in this study. The sample consists of social welfare service users in Aomori area. Our findings, therefore, are generalizable to these users. Our survey doesn't include the people who are not using social welfare services. We can't estimate number of people who are entitled to the AGS in Aomori area.

Notwithstanding the limitation, this study is consistent with previous studies. This study can clarify that most users who are entitled to use the AGS are not using the AGS. Some further development is necessary for future studies. For example, it is necessary to conduct another survey in depth to verify and to examine characteristics of users who need the AGS.

Conclusions

Social welfare service providers were aware that the AGS was essential for users, but they were not sure how to access the AGS. As a result, many users who are entitled to the AGS do not access or use the AGS according to recent surveys, although the AGS is crucial for advocating for users' rights. In the near future, social welfare service providers for users with disabilities will

need information about the AGS more than social welfare service providers for the elderly.

Receiving consultations about the AGS from legal experts and municipalities is useful for social welfare service providers. In joint council, social welfare service providers play an important role to encourage users to participate in the decision-making process.

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*) Hachinohe survey in 2016 was conducted by another research team. We used Hachinohe survey as reference, and revised the Hachinohe survey questionnaire to suit our research purposes.

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