

Feasibility of a Cost-Effectiveness Analysis Examining Interventions for Abused Persons with Intellectual Disabilities

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Abstract: Japan implemented new legislation to prevent the abuse of persons with disabilities on Oct 1, 2012. Many specialists from various domains participated in the development of interventions to prevent such abuse. Here, we conducted a pilot analysis to examine the cost of such interventions and to explore differences in resources. In particular, we compared resources for the assistance of victims with intellectual disabilities with those for the assistance of victims with other disabilities. We requested the enrollment of the anonymous case records of 16 local governments. Thirteen municipal/certified centres reported 41 cases, including 42 victims. Of them, 27 victims had intellectual disabilities. We calculated both the time and human/social resources consumed per case until the resolution of the case. Although the median length of time from the start of the intervention until the solution of the claimed crisis seemed longer in cases abused by their families, an analysis of 22 familial cases did not reveal a significant relationship between the type of disability and the resource. Although the existence of intellectual disabilities did not seem to impact the resource, our method of analysis worked well. The accumulation of more cases is warranted.

Keywords: Abuse, intellectual disabilities, intervention, legislation.

INTRODUCTION

In Japan, the Regional Legal Affairs Bureau has consulted on cases of the violation of basic human rights of persons with disabilities. Besides, municipal social welfare offices have supplied advocacy systems for such persons. Nevertheless, specialized legislation applicable to abused individuals with disabilities is required.

Before the ratification of the Convention on the Rights of Persons with Disabilities, Japan enacted a law nationwide for the prevention of the abuse of persons with disabilities on October 1, 2012. The new law "Law About Abuse Prevention of Persons with Disabilities and Supports of Their Guardians" (Abuse Prevention Act for Persons with Disabilities) (Act No. 79 of 2013) defines five types of abuse that may be inflicted by any of three types of offenders (15 forms in total) and targets victims between the ages of 18 and 64 years, providing a due process protection program for victims (Table 1, Figure 1). To secure equivalent measures nationwide, all local governments (including 1,742 cities and 47 prefectures) were required to establish centres for prevention and advocacy. Anyone witnessing abuse is obligated to notify the centres. Besides, health specialists are encouraged to pursue early detection.

The Ministry of Health, Labour and Welfare (MHLW) annually collect data on the total number of services

provided by each centre. Their periodical report [1] counted 1,311 cases registered by a family member, 80 cases registered by institution specialists, and 133 cases registered by employers during the first 6 months after the implementation of the law. Of them, 48.5% of the 1,329 victims reported by families, 54.5% of the 176 victims reported by institution specialists, and 149 (76.8%) of the 194 victims reported by employers had intellectual disabilities. As part of basic data collected in Japan, governmental surveys [2] have shown that 3.77 million of 3.83 million (98.4%) persons (18 years and older) with physical disabilities, 0.47 million of 0.58 million (81.0%) persons with intellectual disabilities, and 2.69 million of 3.01 million (89.4%) persons with mental disabilities (i.e., persons with psychiatric disorders who have been issued a disability identity card) live in the community. Another report [3] indicated that 76.6% of persons with intellectual disabilities live with their own families, though only 73,000 persons were employed at companies (business institutions with more than five employees). Although the pooled crude odds ratio was 1.60 (95% CI 1.05-2.45) for recent violence for persons with intellectual disabilities [4], actually the number of victims with intellectual disabilities was the largest in Japan. Since many unemployed people with intellectual disabilities live with their families, this may increase the risk of abuse from the family.

An assessment of interventions is needed to check the due process given for each type of abuse. In the MHLW report [1], although the totalled cross-sectional data summarized the activities of centres nationwide, the contents of interventions for individual cases were

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Table 1: Definitions of Abuse in the New Legislation

Type of abuse	Explanation	Perpetrator (setting of abuse)	Explanation
Physical	Bodily injury or such potential assault Arbitrary restriction	Family member(s)	Person(s) substantially in charge of care, with the exception of individuals described below (Including relatives and family-in-laws)
Sexual	Sexual assault, forced to perform sexual behaviours	Institutional professional	Employees of both residential and outpatient facilities for persons with disabilities
Psychological	Verbal aggressiveness, negative or discriminative response leading to psychological trauma	Employer	Entrepreneur or contractor (Including contractors provided by temp agencies)
Neglect	Indifference or inattention to care required		
Financial	Unfair disposal of properties Exploitation of profits (e.g., social securities)		

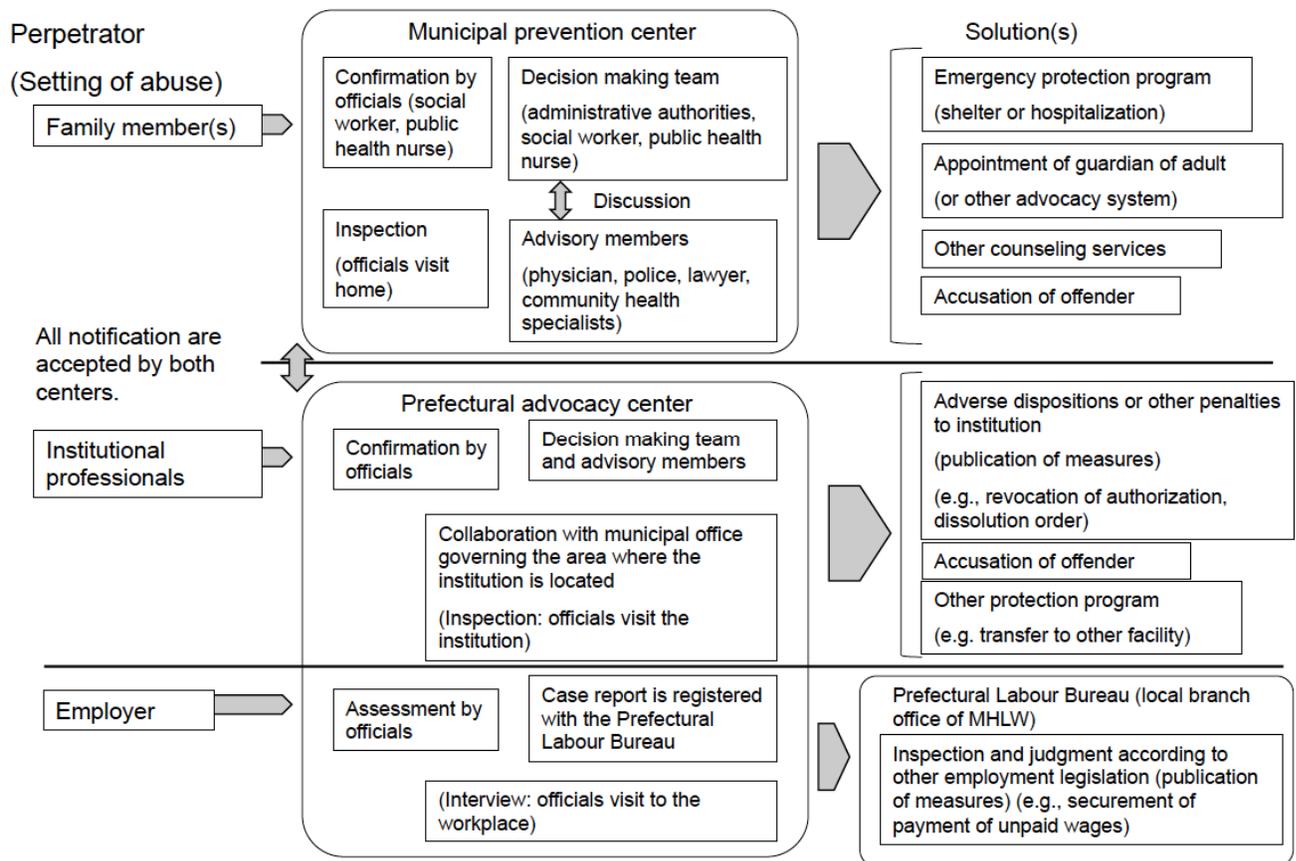


Figure 1: Scheme showing legislative interventions for each type of abuse.

not available. For example, the required workforce of community health workers was estimated based on the number of consumers and the labour cost required to complete the necessary processes required by the act [5]. Moreover, the medical costs were calculated

according to the extent of the utilization of healthcare services; such studies often compared the cost of special care with that of general care [6]. In the case of fixed processes performed by a limited number of professionals, such estimations may be relatively

simple. In interventions for cases of abuse, various professionals are engaged, and the contents of the interventions differ for each case. Because the literature on related issues was not available, a case study is needed to estimate the workforce required by the implementation of the act. To analyze the contents of intervention, we designed a study measuring resources according to time and cost required per case. Apart from international differences in social security systems, such comprehensive works seem to be sparse worldwide despite the magnitude of this issue. Therefore, our trial will be the first report regarding the abuse of persons with disabilities in Japan. We hypothesized that interventions for mental disabilities might require a longer time and/or a higher expense, compared with those for other disabilities.

METHODS

We held preliminary hearings with social welfare officials from 17 local governments to obtain opinions regarding measures of abuse. One city declined to participate, so we requested the anonymous case records from 16 local governments (13 cities and 3 prefectures) that had been recognized as being advanced in regards to this issue before the enactment of the law.

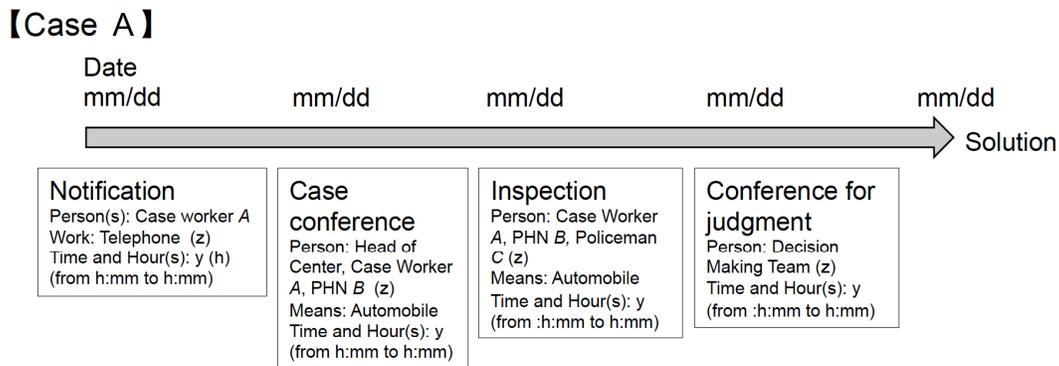
Besides, since we wished to review completed cases despite our study occurring within the first year of the enactment of the new law, we requested case

reports from private counselling centres authorized by Chiba Prefecture. These centres had experienced many cases of abuse as part of an advocacy program created by the Chiba Prefecture Ordinance for the Solution of Discrimination to Persons with Disabilities, which was enacted in 2007 (Act No. 52 of 2007; last amendment Act No. 22 of 2012). After the enactment of the Abuse Prevention Act for Persons with Disabilities, some of these centres were entrusted by the cities where they were located.

We created case records containing information pertinent to our study. The profile for each case included the type(s) of abuse and the offender(s), the onset, frequency, severity, and content of the abusive behaviours, and the characteristics of the victim (gender, age, disabilities).

Besides, we collected details of the interventions performed for each case, including time (date, time required, and duration), experts engaged (number of persons, and their specialities and positions), and the contents of the interventions, describing the interventions in a manner similar to that of a medical record.

We required that the cases included in this study satisfy all of the following conditions: a positive judgment (recognition of abuse having occurred), and the commencement and completion of intervention after the enactment of the law. If no such perfect cases



Detailed data that was as precise as possible was requested.

Consumption for Case A

variables	definition	unit
Days	duration from acceptance of notification until solution	x_a days
Time	actual accumulated working hours	y_a hours
Persons	accumulated number of specialists directly engaged	z_a persons
Labor cost	accumulated labor costs by all persons	$x_a * y_a$ yen

Totaled across cases

Figure 2: Caseload analysis (example).

were available, we allowed the expert in charge of the case to relax the criteria.

To complete each record, experts removed all personal information and recalled the contents of the intervention as completely as possible. They provided a number for each case record in the event that further inquiry was needed. Only the experts in charge of the cases were aware of how the case numbers corresponded to the actual cases.

Case recruitment started in October 2013.

We calculated both the time and human/social resources consumed per case until the resolution of the case. For every intervention, the involvement of professionals was converted into their estimated wages for on-duty hours. In Figure 2, each case record was calculated separately since the salaries of officials vary according to the region and the salaries of employees differ individually, although we adopted identical values for each type of professional to balance the results.

Such medico-economical measurements were validated in our previous study [7].

In the present report, the total time and cost required until a solution was reached were compared according to the type of disability, since the setting of the abuse (a type of offenders) decides the due process.

A multiple regression analysis using dummy variables was performed for the statistical analysis.

This research was approved by the ethical examination board of the National Center of Neurology and Psychiatry (ID: A2013-073). The study protocol met the national ethical guidelines for epidemiological studies.

We converted the work of every person appearing in the case records into an hourly rate equivalent. The wages in Table 2 were drawn from various official publications (Most of the data was cited from reference

Table 2: Table for Labour Costs

Professionals	Hourly wages (JPY)	Included in this study
Psychiatrist (working at Mental Hospital)	7,498	Other physicians
Nurse (working at Mental Hospital)	2,346	Nurse working at other outpatient facilities
Certified psychiatric social worker (working at Mental Hospital)	1,887	Other medical social workers
Occupational therapist (working at Mental Hospital)	2,144	Physical therapist
Other workers (working at Mental Hospital)	1,615	Psychologist
Lawyer (counselling fee per hour)	5,000	Lawyer as an advisory member
Nurse, Public health nurse (PHN) (Municipal officer at the major city)	2,604	PHN as a prefectural administrative official
Social worker (working at private welfare facility)	1,034	Workers at the private advocacy centre
Social worker or other care workers (working at the private institution)	1,426	
Social worker or other care workers (working at the prefectural institution)	2,504	
Municipal officials in administrative service	2,924	
Prefectural officials in administrative service	2,794	
Policeman (prefectural officer)	2,986	
National officials in administrative service	2,352	Officials of The Public Employment Security Office, Prefectural Labour Bureau
Associate professor at a university	3,275	Advisory member as a person of learning and experience
Home helper (home care worker for elderly or persons with handicaps)	1,364	
Care manager (nursing care manager)	1,618	
High school teacher (prefectural officer)	2,819	High school teacher for special needs education

number [8]). Hourly wages were calculated according to the national average monthly salary for every specialist. We ignored differences in age when calculating the average salary of specialities. We calculated an overtime wage of 1.5 times the normal hourly wage for duties performed at times outside of 8:30-17:15 on weekdays or for duties performed on national holidays.

In completing the case records for our study, the speciality of each person involved was required. If the speciality of a person was identified, his/her wage was determined based on that speciality.

RESULTS

As of March 2014, 13 municipal/certified centres reported 41 cases, including 42 victims. Six cases were experienced before the enactment of the law.

Twenty-two victims were females and 20 were males.

Thirteen victims (31.0%) were in their 40s.

The perpetrators were mainly family members or relatives in 22 cases (52.4%), institution professionals in 9 cases, and employers in 10 cases. Among the familial offenders, 8 of the perpetrators had mental disabilities and 1 was suspected of having a mental disability.

The type of abuse was complex abuse in 18 cases and single-type abuse in 22 cases.

Four cases were ultimately judged as not being abuse. Overall, physical abuse was reported in 24 cases, sexual abuse was reported in 4 cases, psychological abuse was reported in 17 cases, neglect was reported in 7 cases, and financial abuse was reported in 10 cases.

The severity of the abuse was rated as mild in 8 cases, moderate in 6 cases, severe in 4 cases, and profound in 7 cases.

Twenty-seven victims in 26 cases had intellectual disabilities. Six victims (14.3%) had 2 or more disabilities, and 12 had mental disabilities. Of these victims, the co-occurrence of different types of abuses occurred in 6 cases (50.0%); 8 cases (66.7%) were abused physically, and 6 cases (50.0%) were abused psychologically.

As a solution, a guardian was appointed in 5 cases. Separation or institutional hospitalization was performed for 6 cases. The perpetrators had died in 2 cases; among the registered cases, none of the victims had died.

The total number of interventions among all the records was 1,724; of these interventions, 55 were performed during off-duty hours.

Among the victims with intellectual disabilities, 22 (53.7%) were victims of familial abuses, 9 (22.0%) were victims of institutional abuse, and 8 (19.5%) was abused by his or her employer.

Table 3: Differences in Median Values According to the Presence of an Intellectual Disability

Variables		Whole sample (n=41)	Intellectual disability	
			without (n=15)	with (n=26)
(a) Days of intervention (days)		15	17	11
(b) Total number of days (days)		17	17	14
(c) Total length of time for intervention (h)		15.38	17.25	9.5
(d) Total number of specialists working for intervention		33	50	30.5
(e) Total amount of time spent for each intervention (h)	talking on the telephone	2.25	1	2.58
	Conference	4.5	8	3.5
	decision-making conference (other than above)	2	2	2
	confirmation of facts	2.25	4	2
	visits for inspection	3.75	5.38	3.25
	accompanying visit to hospitals (both perpetrators and victims)	4.5	4.5	4.5
(f) c*d summed for each case		35	53	25.5
(g) Total labor cost for each case (JPY)		76,330.5	138,701.83	54,541

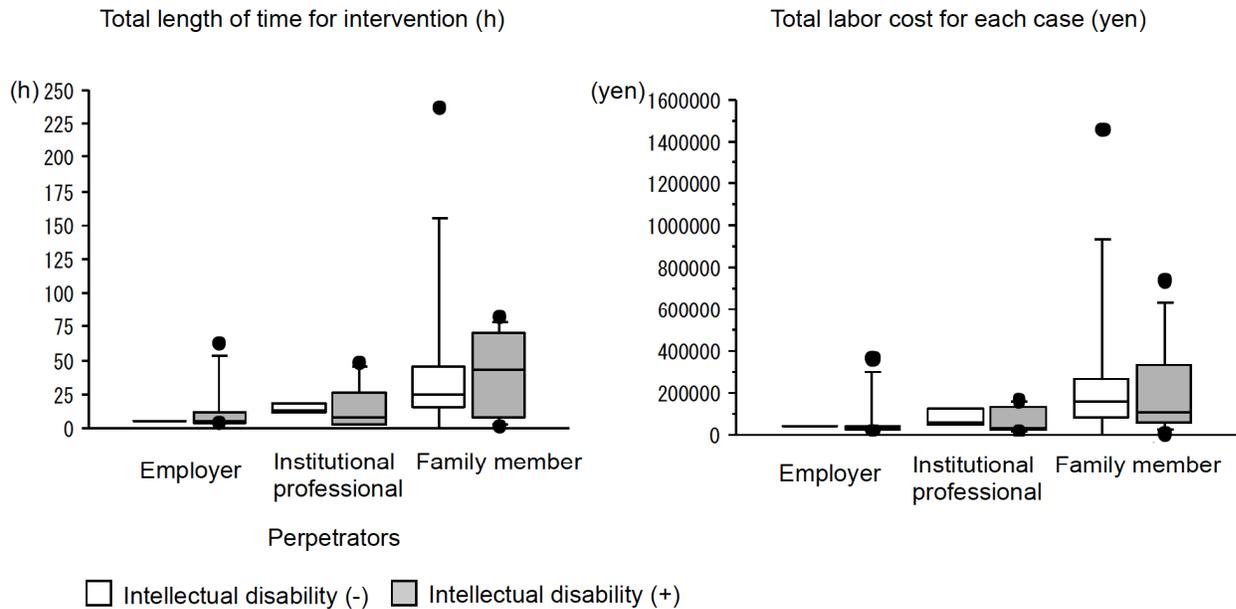


Figure 3: Distribution of data for two variables according to presence of intellectual disabilities.

The median length of time from the start of intervention until the resolution of the claimed crisis was 14 days for the cases with intellectual disabilities and 17 days for the other cases.

The median values seemed to differ depending on where the cases had been abused; familial cases required the higher total labour cost, as indicated by the number of hours worked by specialists and longer interventions.

The box plots in Figure 3 show the distributions of time (left) and cost (right) consumed by the intervention sorted according to the perpetrators. Each box shows the upper (75th percentile) and lower (25th percentile) quartiles of the distribution, while the horizontal line inside the box shows the median. The dots located above and below the whiskers are outliers. The data for persons with intellectual disabilities seemed to be higher, compared with those for persons without intellectual disabilities. Moreover, the cases of abuse by family members seemed to have a broad range of required interventions.

Many victims had more than one disability, and the existence of each disability was not exclusive of other disabilities. Therefore, the existence of each disability was regarded as an independent variable, and the total time and cost required until a solution was reached were regarded as dependent variables.

An analysis of the 22 familial cases did not reveal a significant relation between the type of disability and

the resource (time: $F = 0.66$, $p = 0.63$, $r^2 = 0.13$, labor cost: $F = 0.84$, $p = 0.52$, $r^2 = 0.16$). An analysis using two classes of factors simultaneously (disabilities and type of abuse) could not be performed because of the small sample size.

DISCUSSION

Many researchers have found a higher prevalence of sexual abuse among persons with intellectual disabilities [9-13]. These reports often focused on sexual abuse, probably because of the nature of the cases, although a review [9] concluded that persons with intellectual disabilities experienced other types of abuse as well. Only a few reports were available regarding other types of abuse and on the situation surrounding the abuse.

In many reports [9, 11-14], the perpetrators of sexual abuse were out-of-family members, and such findings were observed internationally. However, sexual abuse conducted by family members or caregivers was not rare because persons with intellectual disabilities often depend on and overconfide in others throughout their life [12]. In Japan, a ministerial report [1] revealed that the majority of perpetrators were family members across the different types of abuse; thus, the act defined the measures for abuse according to the settings of the cases (i.e., the perpetrators).

Few reports have discussed the causes of abuse, and abuse often concurs with a constellation of other

risk factors, such as a young parental age and hospitalization for mental health [15]. In many cases, both the perpetrator and the victim had a mental disability. More than half of the presently reported cases were abused by their families, and many of these perpetrators had a mental disability. The prevalence of intellectual disabilities and mental disabilities resembled the results of a national report. Thus, our sample did not deviate remarkably from the overall results for Japan. In Japan, the higher frequency of family members as perpetrators might be explained by the higher rate of persons with intellectual disabilities who reside with their families [3] and, consequently, the lower rate of social participation (i.e., employment). To prevent abuse in families, social resources within the community, such as daycare centres, are needed not only to provide free time to both sides but also to check for maltreatment.

Determining the contents of interventions for abused individuals with disabilities will help to standardize the expected resources for each type of disability, enabling local governments to set budgets sufficient to cover the predicted annual costs.

The cost of the abuse of individuals with intellectual disabilities did not differ in our sample. Cases with intellectual disabilities did not require a significantly longer time or cost until a solution was reached, compared with cases with other disabilities. We are convinced that all the experts involved with the interventions for these cases met their responsibilities appropriately. Therefore, our results suggest that local governments can set budgets based on the number of anticipated cases. Of course, all the centres in the present study employed experts who specialized in helping abused individuals with disabilities. The training of additional members is necessary.

Our study had various limitations, such as the relatively small number of cases and a mixture of cases with diverse conditions. However, our analysis method worked well and such studies were shown to be feasible. A model that can effectively predict the resources based on the case profile could be obtained using a larger sample. Lack of data is an obstacle to addressing the abuse of persons with intellectual disabilities [9]. Consequently, the accumulation of more cases is warranted.

Further studies are expected to evaluate consumers' satisfaction with the outcome of the intervention. Rescued persons or their advocates will

be encouraged to rate the outcome. If a discrepancy is found between published outcome and satisfaction, stakeholders (e.g. specialists of intervention team) will control the quality of their intervention; consequently, the government will be motivated to revise the process and measures prescribed in the Act.

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