

<i>Method</i>	B: life care	
Work code		B1, 2, 3: patient hygiene, grooming
		B4, 5, 6: clothes changing
		B7: bathing
		B8: toilet support
		B9, 10, 11: meal assistance
		B12, 13, 14: posture change
		B15, 16, 17: transfer to/from wheel chair
		B18, 19, 20: patient transfer
		B21, 22, 23: posture support
		B30, 31, 32: temperature taking
		B33, 34, 35: indirect patient assistance
		B36, 37, 38: environmental organization
		B40: bed/linen organization
		B41: laundry
		B42: organization of patient goods
		B45, 46: communication
	B49: supervision	
	B50: others	

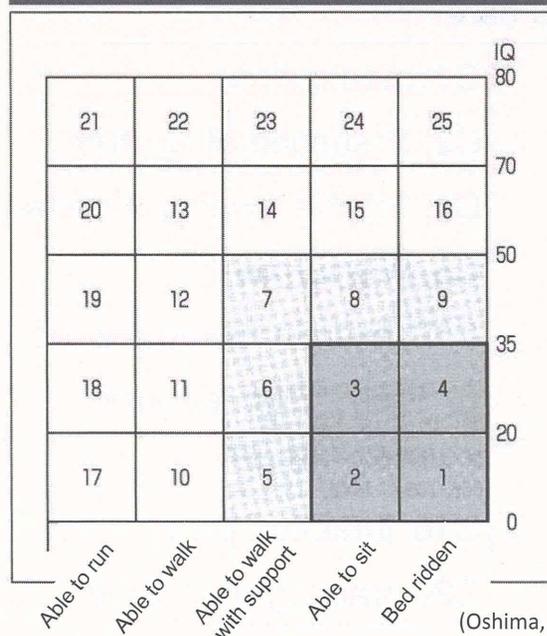
Work code	C: medical care	
		C1: medication
		C2, 3: suction of sputum
		C4, 5: tube feeding assistance
		C8, 9: treatment
		C10: examination/measurement
		C11: physician support
		C14: hydration
		C16: infection prevention
		C20: training (non-professional)

Profiles of the client

ID	age	sex	underlining disease	Oshima's classification	SMID-MCDG score
1	24	F	CP	5	0
2	40	F	MR, motor retardation	10	5
3	49	M	CP	10	0
4	6	M	CP	1	11
5	23	M	CP	1	13
6	44	M	MR, Diabetes	11	5
7	37	F	Down's syndrome	12	0
8	22	M	MR, Epilepsy	2	5
9	37	M	Down's syndrome, Diabetes	12	0
10	19	F	Chromosomal abberation	10	0
11	19	M	CP	6	0
12	8	M	Myotonic dystrophy	2	24
13	52	M	CP	16	8
14	62	F	CP	4	8
15	52	M	CP	9	8
16	10	M	Dandy-Walker syndrome	1	11
17	18	M	CP	7	0
18	43	F	CP	4	0
19	20	M	CP	1	27
20	33	M	MR, Epilepsy	5	5
21	13	F	Arnold-Chiari malformation	1	5
22	8	M	Congenital hydrocephalus	5	5
23	10	F	Chromosomal abberation	5	0
24	21	M	CP, Epilepsy	1	27
25	12	F	CP, Epilepsy	1	22

Underlining disease should be childhood onset.

Oshima's Classification for SMID (1971)



Underlining disease should be childhood onset.

<i>Result</i>		staff ID	occupation	supervision	stimulative speech	direct care	work content	work code	time of the beginning	work time (min.)
Care of client 1-1 Oshima's Classification 5		3	child counselor				arriving at client's home	B17	9:26	1.0
		9	nurse				arriving at client's home	B46	9:26	1.3
							communication		~	
							transportation	D16	9:27	
		3	child counselor				transportation	D16	9:29	1.0
							communication	B46		
		9	nurse				transportation	D16	9:53 ~ 10:02	2.0
							communication during transportation	B46		
							transportation	D16		
		3	child counselor		1	1	patient transfer	B20	10:13 ~ 10:15	3.0
						1	patient transfer			
						1	patient transfer to the room			

<i>Result</i>		staff ID	occupation	supervision	stimulative speech	direct care	work content	work code	time of the beginning	work time (min.)
Care of client 1-2		7	nurse	1	1		temperature taking	B32	10:15	1.0
				1	1		making record of the care	A7		
				1	1		information exchange between staffs	A4		
		8	kindergarten teacher		1		temperature taking	B32	10:15	2.0
		5			1		communication	B46		
		9	nurse		1		stimulative speech	B45	10:21	1.0
					1		temperature taking	B32		
		2	child counselor		1		communication	B45	10:28	2.0
		1	nurses' aid		1		recreation (individual)	D6	10:30	3.0
			kindergarten teacher		1	1	read parent note	D6	10:41	1.0
		5	kindergarten teacher		1		toilet support	B8	10:43	5.0
		1	nurses' aid		1		recreation (card play)	D2	10:49	1.0
		1	nurses' aid		1		recreation (card play)	D2	10:51	1.0
		2	nurses' aid		1		recreation (group)	D2	10:54	1.0
		3	child counselor		1		recreation (individual, card)	D6	10:54	1.0
		8	kindergarten		1	1	recreation (group)	D2	10:54	1.0
		3	child counselor		1		recreation (individual)	D6	10:56	2.0
		8	kindergarten		1	1	recreation (group)	D2	10:57	1.0
		1	nurses' aid		1		recreation (group)	D2	11:01	3.0
		7	nurse	1	1	1	recreation (individual)	D6	11:01	1.0
		3	child counselor		1		recreation (individual)	D6	11:06	1.0
		8	kindergarten		1	1	recreation (group, card)	D2	11:06	1.0

<i>Result</i>		staff ID	occupation	supervision	stimulative speech	direct care	work content	work code	time of the beginning	work time (min.)		
Care of client 24-1	3	child counselor				arriving at client's house	D16	9:30	~	3		
							B46					
				1	1	transportation	B17					
				1	1		A3					
						departure	D16	9:32				
							B46					
Oshima's Classification 1	7	nurse	1			departure	B49	9:33	~	3		
			1				D16					
						1		C2				
						1		C3				
						1		D16				
						1		C2		9:35		
						1		C3				
						1		C16				
					1	1	1	put a cap on the head	B49	9:37		3
					1	1	1		B46			
					1	1	1		D16			
					1		1		B49			
					1		1		D16	9:38		
					1		1		B30			
			1		1		B49					
			1		1		B31	9:39				
			1		1		B32					

<i>Result</i>		staff ID	occupation	supervision	stimulative speech	direct care	work content	work code	time of the beginning	work time (min.)
Care of client 24-2	7	nurse		1				B32	9:40	7
				1				B46		
				1			D16			
			1				B49			
			1				D16			
			1				B49			
			1				D16	9:46		
				1			D16			
			1	1			B49			
			1	1			B46			
			1				D16			
			1				B49			
					1		D16	9:47		
					1		C2			
					1		C3			
					1		D16			
					1		C2	9:48		
					1		C3			
			1				B49	9:52		
			1				D16	9:59		8

Result

Time and content of care for client 1 and 24

I. direct work (min.)			
work code	contents	client ID	
		1	24
A	life support or care management	7.9	0.5
B	life care	88.6	92.0
C	medical care	0.6	92.7
D	social participation support	77.4	75.8
E	community life support	0	0
F	others	1.0	0
care time of the client (min./day)		175.4	261.0
days of attendance		3	1
total care time of the client (min.)		526.3	261.0

Result

Time and content of care for the clients

I. direct work																		
work code	contents	client ID																
		1	2	3	4	5	6	7	8	9	10	11	13					
A	life support or care management	7.9	2.0	0.9	6.0	2.1	2.2	0.8	0.5	1.6	0	1.3	4.5					
B	life care	88.6	117.8	65.3	101.3	197.8	77.8	15.0	55.3	50.6	33.0	47.7	82.5					
C	medical care	0.6	1.6	0.3	11.0	13.0	7.0	2.7	6.5	2.8	0	0	12.0					
D	social participation support	77.4	33.8	30.5	85.2	86.3	35.1	14.3	38.8	11.7	31.0	63.5	32.5					
E	community life support	0	0	0	0	0	0	0	0	0	0	0	0					
F	others	1.0	0	0	0	0	0	0	0.5	0	0	0	0					
care time of the client (min./day)		175.4	155.2	97.0	203.5	299.3	122.2	32.8	101.5	66.6	64.0	112.5	131.4					
days of attendance		3	3	3	2	2	3	3	1	3	1	1	2					
total care time of the client (min.)		526.3	465.5	291.0	407.0	598.5	366.5	98.5	101.5	199.9	64.0	112.5	262.8					
work code	client ID											total	average (n = 23)	common work				
	14	15	16	17	18	19	20	21	22	23	24				25			
A	1.5	0.8	0	2.5	1.2	4.0	15.0	11.5	3.0	9.0	0.5	9.0	87.8	3.8	512.6			
B	95.3	94.7	71.0	42.0	102.0	95.7	0	141.0	141.8	51.5	92.0	53.0	1912.6	83.2	298.6			
C	0.9	0	4.0	0	1.0	29.5	0	18.0	21.0	26.0	92.7	34.5	285.0	12.4	31.0			
D	45.1	34.5	24.5	6.5	57.7	133.5	0	55.0	53.5	9.0	75.8	15.0	1050.2	45.7	1391.2			
E	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0			
F	0	0	0	0	0	0	0	0	0	0	0	0	1.5	0.07	321.9			
care time		142.8	130.0	99.5	51.0	161.8	262.7	15.0	225.5	219.3	95.5	261.0	111.5	3337.0	145.1	2,555.3		
days		2	1	1	1	1	0	1	1	1	1	1	39			min. / day		
clients total		285.7	130.0	99.5	51.0	161.8	262.7	0.0	225.5	219.3	95.5	261.0	111.5	5,397.5		min. / 3 days		
II. common work																		
occupation (total days of work)	nurse (7)	nurses' aid (3)	child counselor (11)	kindergarten teacher (6)	PT (2)	subtotal (min./day)	total (min./ days)											
common work (min.)	598.2	257.0	1,131.5	568.6	23.2	2,555.3	7,665.9											

confirmation : 13, 063.4 min. (total work time : 5, 397.5 + 7, 665.9) / 29 (staffs' total work day) / 60 = 7.51 (hr)
 ← work time of each staff per day

Summary Average care time for one client was 145.1 minutes/day (A: 3.8, B: 83.2, C: 12.4, D: 45.7, E: 0, and F: 0.1 minutes). Total work time was 3,337.0 minutes/day. Care was provided by child counselors, nurses, kindergarten teachers, the nurses' aide, and the physical therapist in this order. Staff also engaged in 2,555.3 minutes/day of common work such as transporting clients and preparing for activities.

Conclusions Results show that **nurses** were engaged in life care or social participation as well as medical care. Through daily interaction, nurses can gain **a good understanding of individuals' conditions**. This will contribute to improved life expectancy of persons with SMID/PIMD. At the same time this will be an important theme for supporting lives of children and persons with SMID/PIMD living at home wherer medical resources are insufficient.

③ Present condition of daycare services for children and adults with SMID

Takashi MITO (Nikoniko-house Medical and Welfare Center, Kobe, Hyougo, Japan)

Sachio TAKASHIMA (Yanagawa Institute for Developmental Disabilities, Yanagawa, Fukuoka, Japan)

Background The system of tuenjigyō (daycare program for children and adults with SMIDS) has developed for more than 20 years in Japan. The number of the institutes is more than 300 and about 6000 people with SMIDS use this system now. However, there are several problems which should be solved. Therefore, we performed questionnaire investigation to clarify these problems. Here we report the results of the investigation and the discussion on their countermeasure.

Methods Examination charts of questionnaires were delivered to 310 institutes servicing with tuenjigyō. The questions included the very important problems in the area of the institutes and the means for settling those problems. And the content and condition of their utilization, actual needs of their transportation, and the management of the tuenjigyō were also asked.

Result Replies from 177 institutes (withdrawal percent: 57.1%) showed that the most important subject is an insufficiency of the number of institutes and the space for daycare in each area. The medical problems also included the insufficiency of the number of nurse, the lack of emergency system, the cost of the transportation for users and the economic management of institutes. Against the theme of lack of the institution, some suggestions were proposed as countermeasure. And there were many opinions that the administrative financial support is necessary.

Conclusion Using the cooperation between institutions and government, we should cope with the subjects containing the increase of the institution in quality and quantity, making medical level up, establishment of the comfortable transportation and the construct of tuen daycare system in each regional area and making the best of social resources.

Daycare services for children and adults with severe motor and intellectual disabilities in Japan

Takashi MITO, Sachio TAKASHIMA

The service system for day to children and adults with severe motor and intellectual disabilities –abbreviation SMID – was established more than 20 years ago in Japan. Presently, numbers of institutions are counted more than 300 and withholding about 6000 persons with SMID.

Medical daycare service program is very useful for the welfare of SMID persons in living at home. The institution is a necessity for persons with SMID at home in Japan.

【 Daily schedule 】

The slide shows a time table for the client who spend a day time at the day care center in a community. Longer times are being spent for gardening, cooking, bowling, soccer, and kara-oke singing. These are occupy 28 % of total hour spent at the center, namely between 5 to 6 hours stay. Then 22.9 % for lunch and supplying the water, 10.6% of discharge of bodily wastes, 8.5% of exercise, morning and end of the day meeting for 7.7%, 5.2% for exam-medical, 3.6 % of bathing, and 13.5% for others.

【 Weekly schedule 】

Data obtained present how one week is spent by SMID client who lives at home. 32.9 % of total time is used to spend at the center. Adding the 12.8% of time that spent at the other center, it become 45.7% which equivalent to approximately 3.2 days. On the other hand, 45.5% is spent at home which is approximately 3.2 days. 8.9 % (approximately 0.6 day) are for other miscellaneous use that include hospital visit, short stay at the center and going out into town.

【 Average number of users and stuffs 】

Average capacity of a day care center throughout of Japan is 11.8 persons. Average numbers who made a registration to the center was 22.3 persons.

On the other hand, average numbers of staff employed at the center is 7.1 persons including full time and part time employee, among which, 1.8 person for nurses and 4.4 person for care giver.

【 Age of users 】

Initiation of day care center for SMID person was started by the problem seen among SMID who finished high school had no place to go, eventually have to stay at home all the time. Therefore, users of day care center were mostly by those who had finished high school education and adult SMID.

After 20 years passed, centers only subjected for adult client, and not subjected for child client have decreased as for 36.7%. On the other hand, there are 58.0% of centers where accepting child client. Furthermore, a centers accepting client under the age of 17 is 5.3%.

【 Methods 】

Survey was carried out by mailing the questionnaire to 310 centers throughout of Japan. Questionnaire form was structured focused on the subjects suspected to be major issues in the community, namely, inadequate numbers of center and the size of facilities, medical care system, transportation service from homes to the center, administration and management of the center, and a system of day care center in a given area.

【 Insufficiency of the institutions 】

Response rate was 57.1%, which replied by 177 centers.

Major issue was inadequate numbers of center. Also complaint was made for insufficient size of space at the center.

Among those claimed, there was a claim such as “the center is existing to accept SMID client, but the one with medical care for severe case is insufficient. In such an area, also the center able to provide a medical care for light degree is insufficient

There was a comment saying, no more capacity at the center with present users saturated the capacity, so that students who are taking a long school off or a graduate from high school found no place to go in.

【 Medical care service 】

There are comments on how to gain, maintain the number of nurses, brush up the medical knowledge and technique for care givers and the necessity to facilitate a function for medical emergency case occurred are seen in fairly large numbers. Also, desire to ward financial aid for such facilitation was found

【 Transportation 】

A problem presented during transportation service was that of medical care in the care when emergency case occurred. In case the transportation course are too many, how can arrange the nurse to all would be a problem. In another words, how can we have a sufficient number of nurse at the center to assign on the car.

Cost for the car, maintenance cost, cost for fuel, cost for drivers are also causing problems. In addition, some place, it makes difficult to maintain a service function due to snowing in winter.

【 Management and administration of the center 】

As an essential nature of the day care center for SMID client, it requires more manpower and over cost to maintain, so that insufficiency of budget will cause under the present welfare system. Income is proportionately increase as the users increase, so if the client absent to come to the center for some reason, it makes decreasing of the income.

On the other hand, there are demand to open the center in weekend or extended hours would help to increase the income, but it requires over cost for man power and it rather cause the reduction of total profit.

【 A system of day care center in a given area 】.

If the center should be made in relation with the size of community and its population more centers should be facilitated in ever communities.

Having the center specialized only for SMID client would be impossible, alternative solution would be utilizing the facilities subjected for aged person or hospital where medical approach are available. In case of such a solution, there is a need of talks and discussion involving with various fields such as other type of centers or government administrative

offices.

【 Summary 】

It is obvious that an existence of day care center where SMID person can spend a time daily with much joy, would be effective to bring up their QOL. According to the data we obtained, it seems that the demands were great for the vehicle which is equipped with medical care, secured transportation and for short distance to reach to the center were great.

However, it is considered that getting sufficient number of day care centers for SMID client in the community takes long time to accomplish. As for an alternate solution, collaborative work with other centers in a community and with the government administration backed up by law and financial support would be greater demands in future.

Daycare services for children and adults with
severe motor and intellectual disabilities in Japan

Takashi MITO ¹, Sachio TAKASHIMA ²

1 Nikoniko-house Medical and Welfare Center, Hyogo, JAPAN

2 Yanagawa Institute for Developmental Disabilities, Fukuoka, JAPAN

Program of medical daycare services for patients
with severe motor and intellectual disabilities (SMID)

Year of start	:	1990
Number of institutes	:	310
Number of users	:	about 6000

Daily schedule in the institution

	Distribution of times
Playing	28. 0
Lunch	22. 9
Toilet	10. 6
Exercise	8. 5
Meeting at beginning & ending	7. 7
Medical treatment	5. 2
Bath	3. 6
Others	13. 5 (%)

Weekly schedule of the users' daytime

	Rate of dayly living place
Daycare service	32. 9
Other daycare services	12. 8
Home	45. 5
Others	8. 9
	(%)

Age distribution of users in the institution

Both children and adults	58. 0
Less than 17 years of age	5. 3
Over 18 years of age	36. 7
	(%)

Average number of users & stuffs

	Number of persons
Capacity per a day	11. 8
Registration of users	22. 3
Number of stuffs	
(conversion to full-timer)	7. 1
Nurses	1. 8
Care workers	4. 4

Methods

Questionnaires were delivered to 310 institutions in which the item of query are included as follows :

- Insufficiency of the institutions
- Medical care service
- Transportation
- Management and administration of the institution
- A system of day care center in a given area

Insufficiency of the institutions

- Services to the patients with severe medical problem
- Additional institution for mild medical patients
- For students during long vacation and post graduation

Medical care service

- Difficulties of having nurses to serve and keeping them
- Education of staffs with medical knowledge and skill
- System to serve for emergency case
- Financial aid

Transportation

- Establishing ambulatory system
- Cost for vehicles and its drivers and the fuel
- Measures to deal with snowing in the winter

Management and administration of the institution

- Countermeasure against the high personal expenses
- Protect of income against users' absence
- Services of prolong working time and opening on weekend for users

A system of day care center in a given area

- Regulation of the institution in each area
- Practical use of social resources including institution for the aged or general hospital
- Cooperation with other institutions and government

Summary

- 1 Survey had been carried out by sending questionnaire by mail to the day care center throughout of Japan.
- 2 Major claim was that of insufficient numbers of the day care center. Claims were followed by medical care system, transportation, administration and management of the day care center, a system of day care center in a given area.
- 3 Comment was seen that collaborative work with other centers and local government in order to make a progress of the system for day care center system.

II - 8. 国際学会での発表

(2) IASSIDD PIMD 特別研究グループ円卓会議 ポスター発表

○末光 茂, 水戸 敬, 曾根 翠

2013年10月23～25日にオランダ・グローニンゲンで開催された IASSIDD PIMD 特別研究グループ円卓会議において、2年間の研究成果を発表した。その内容を掲載する。

Present condition of daycare services for PIMD in Japan

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Takashi MITO	Nikoniko-house Medical and Welfare Center, Kobe, Hyougo, Japan
Sui SONE	Tokyo Metropolitan Higashiyamato Medical Center For Developmental Multiple Disabilities, Tokyo, Japan

Background In Japan (12million population) we have 37thousand PIMD persons and 25thousand PIMD persons live with their own families. The system of daycare program for PIMD has developed for more than 20 years in Japan. The number of the facilities is more than 310 and about 6000 people with SMIDS use this system now. There are several problems which should be solved. We performed questionnaire investigation to clarify these problems. Here we report the results of the investigation and the discussion on their countermeasure.

Methods Examination charts of questionnaires were delivered to 310 facilities. The questions included the important problems in the area of the facilities and the means for settling those problems. And the content and condition of their utilization, actual needs of their transportation, and the management of the daycare program for PIMD was also asked.

Result Replies from 177 facilities (withdrawal percent: 57.1%) showed that the most important subject is an insufficiency of the number of facilities and the space for daycare in each area. The medical problems also included the insufficiency of the number of medical nurse, the poor emergency system, the cost of the transportation for users and the economic management of facilities et al.

Present condition of daycare services for SMID (PIMD) in Japan

Shigeru SUEMITSU, Takashi MITO, Sui SONE

【 P1. SMID/PIMD in Japan 】

The population of JAPAN is about 128million.

The number of SMID /PIMD is about 43,000 persons. The number of those who stay in institutions is 19,000, those who stay at home is 24,000. The rate of them which need intensive medical care or semi-intensive medical care is about 30%.

【 P2. Age Distribution Curve of home and residential care clients (2013) 】

The age distribution curve of those who stay at home is younger that of institutional care clients.

【 P3. Present situation 】

This is present situation of Japan. The number of residential Institutions for persons with SMID is 196, which offer 19,400beds.

The number of Day Care Centers is 310, which accept 6,000 clients.

Users of short stay service are 200thousand man-day last year.

Usually persons with SMID staying at home use Home visiting Nurse, medical rehabilitation, personal care assistance, home bathing service,etc.

【 P4. Program of daycare services for persons with SMID(PIMD)】

The service system of daycare for persons with SMID started more than 20 years ago in Japan. Among 6000 uses of daycare centers, 30% need intensive or semi-intensive medical care.

【 P5. Methods 】

Survey was carried out by mailing a questionnaire to 310 daycare centers throughout of Japan. Questionnaire form was structured focused on the weekly daytime schedules of the users, the activities of daycare centers, insufficiency of daycare facilities, medical care service, transportation, management and administration, and local system of the day care service where each center located. Response rate was 57.1%, which replied by 177 centers

【 P6. Weekly schedule of the user's daytime】

Data obtained from the clients of each daycare center. Weekly schedule means where