

2 - (8) 国際学会での発表

A . IASSIDD第3回アジア・太平洋発達障害会議 シンポジウム

2013年8月22日、東京・早稲田大学で開催された IASSIDD 第3回アジア・太平洋発達障害会議で2年間の研究成果を、末光らのコーディネーターのもと研究分担者3名がオーストラリアの発表者とともにシンポジウム形式で発表した。その内容を掲載する。

コーディネーター

末光茂, Coleen Adams

シンポジスト

(1) 長岡療育園園長 小西 徹

「A review of services to persons with severe motor and intellectual disabilities in 5 daycare centers over 23 years」

(2) 熊本大学医学部附属病院特任教授 松葉佐 正

「Time study on the care of individuals with severe motor and intellectual disabilities at a day-care center」

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

(4) Newcastle大学助教授 Michael Arther-Kelley

「Sustaining implementation: Design and delivery elements in two recent special education professional development initiatives for staff working with students who have complex needs」

(1) A review of services to persons with severe motor and intellectual disabilities in five day-care centers over 23 years

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Background In Japan, day-care services for persons with severe motor and intellectual disabilities (SMID) were established in 5 centers in 1990. We reviewed the experiences of these 5 centers since their inception.

Method A total of 782 persons with SMID attended the 5 day-care service centers over the 23-year period. We reviewed data including the severity of their disabilities, their medical care requirements, the age at which they entered and left the center.

Results 672 individuals (86.8%) had markedly severe disabilities with Oshima's scores of 1-4. 183 cases (23.4%) required extremely intensive medical care: 38 with ventilator care, 84 with tracheotomy, 211 with frequent air-way suction, and 299 with tube feeding.

The severity of disabilities and medical care requirement increased each year. 353 individuals are currently using the service (Group A). 123 individuals have subsequently been hospitalized to SMID institute (Group B). 115 individuals died while receiving services at one of the centers (Group C). The age at which individuals used the centers varied widely 1 to 59 years, and showed two peaks at pre-school age and post-graduate age. The average duration of utilization was 8 years (Group A: 10.1, Group B: 9.2, Group C: 6.9), and 147 cases continued to use service for over 15 years. Different kinds of care or support were provided, such as daily-life care, medical care, and habilitation.

Conclusions Day-care services which can provide medical care are very important and necessary for the welfare of persons with SMID living at home. These centers are useful for their daily activities, maintenance of general health, developmental habilitation, and also education.

A review of services to persons with severe motor and intellectual disabilities in five day-care centers over 23 years

<Slide 1> INTRODUCTION

Day-care service for persons with severe motor and intellectual disabilities (SMID) was established in 5 institutes in 1990. Thereafter, number of institutes were gradually increased, and being now more than 300 institutes, in Japan. And, about 6,000 persons with SMID utilized these services. These day-care services may contribute to keep stable health and daily-activities for persons with SMID living at home.

There were two types of institutes: type A is 15 fixed persons per day, and with medical care and with transport system, and type B is 5 fixed persons per day mainly for regional service.

<Slide 2> OBJECT

The day-care service restricted to SMID was started from 1990, and was continued for 23 years. In 2012, this service system was shifted to the new ones of divided into child and adult service and involved services to the other kinds of handicaps.

In this study, we reviewed the experiences of these 5 day-care centers since their inception. And, we want to clarify as follows: (the 1st) a role of achievement and utility of these services for SMID living at home, (the 2nd) problems and difficulties on practice, (the 3rd) further what service being effective or better.

We wish to propose to the new system regarding as the consequence of this study.

<Slide 3> SUBJECT and METHOD

The investigation was done in 5 day-care centers, which are Hokkaido Ryoikuen, Nagao ka Ryoikuen, Yokohama Ryoiku center, Asahigawa-so Ryoiku center, and Hisayama Ryoiku center. Their location illustrated on right-side Japan map.

Examination contents were as follows: the 1st number of users for 23 years, and users profile as to the severity of handicaps, requirement of medical cares, the 2nd state of using the center as to the age at start and stoppage of using, duration of utilization, and turning points of using, and the 3rd actual daily activities and cares in the centers.

<Slide 4> RESULTS

Total 782 persons with SMID used these 5 day-care centers during 23 years, mean 156 persons per center. Number of users rapidly increased just after the start of services, and being 2 or 3 holds of the fixed number. It suggests respective centers may cover the area with a population of 5 to 7 hundred thousand. Transport (home to center) was extensive far from 20 to 100 km area.

<Slide 5>

Severity of handicaps revealed according to Oshima's classification score. The SMID in a narrow sense (Oshima's score 1 to 4) occupied in 79.3 to 94.5 percent (mean 86.8 percent). This incidence was almost same to that of in-patients of SMID institutes. More severe case especially Oshima's score 1 tended to increase each year.

As to the time of brain-injury, pre-natal injury is 26.3 percent, peri-natal injury 51.2 percent, and post-natal 22 percent.

<Slide 6>

This slide shows the requirement of medical care of the users. Total 8.3 percent of cases was recognized to IMC required with intensive medical care (Suzuki's score over 25 points), and 15.1 percent of cases was SIMC with semi-intensive medical care (score 10 to 24). Cases both IMC and SIMC were needed to habitual medical care and observation in the center. Incidence of IMC and SIMC was also same to that of in-patients. As to the principal medical cares, 4.9 percent of cases required with ventilator care, 10.7 percent with tracheotomy, 27 percent with frequent air-way suction, and 29.3 percent with tube-feeding.

Cases with ventilator care abruptly increased since 2008. Many of them were from the discharge to neonatal intensive care units (NICU).

<Slide 7>

This shows the turning points of using the services. The cases of currently using the services were 353 persons (Group A), cases hospitalized to SMID institutes while utilization 123 persons (Group B), cases death while utilization 115 persons (Group C), and others 198 persons, who left the centers caused by entrance into specific school, removal, change to out-patient management, etc.

< Slide 8>

Age at the start of using services was widely varied from 1 to 59 years old, and showed two peaks at pre-school age (26.9 percent) and just after post-graduate age (28.3 percent). Among the individual centers, the distribution of start ages was slightly different. B and A center was mainly post-graduate cases (service for adult), C center diversity pre-school cases (service for child), and D and E center all ages.

< Slide 9>

This shows the duration of utilization in Group A (currently using cases). Start ages of using ranged 11.9 to 20.8 years old, mean 15 years. And, duration of utilization ranged 7.8 to 13.1 years, mean 10.3 years. It is remarkable that about 30 percent of cases continued to using for over 15 years. Furthermore, 52 cases continued for 23 years from the start of this service.

<Slide 10>

This shows the duration of utilization in Group B (hospitalized cases in SMID institute). Start ages of using ranged 16.8 to 25.6 years old, mean 21.6 years, which was slightly high compared with that of Group A. Duration of utilization was 9.2 years, which was no obvious difference to Group A. Rate of hospitalization was not so high in the cases with IMC and SIMC.

<Slide 11>

This shows the duration of utilization in Group C (death cases while using the service).

Start age of using ranged 11.3 to 20.9 years old, mean 13.8 years, which was slightly low compared with those of Group A and B. Duration of utilization was 6.2 years, which was obviously short. About a half of the cases died within 5 years utilization. Rate of death in IMC cases was 23 percent, being slightly high.

<Slide 12>

This shows actual daily activities and cares in the centers. Individual program was designed for their quality of life. Daily activity corresponding to their handicaps was done, for example, in severe cases, input of various senses (sensory, auditory, visual, and vestibular) was done for main activities, and habilitation (PT, OT, and ST) was also regularly performed. In mild cases, dynamic activities included outside and production works were done for individual levels. As to the daily care, almost all cases were necessary for many supports of daily-life, such as body change, eating, excretion, body cleaning, etc.

These daily activities and cares produce regularity of daily life cycle, which may be directly related to their quality of life.

<Slide 13> SUMMARY

The 1st: Needs for day-care services (specified to SMID) were many and strong, so the centers always received 2 or 3 holds persons. And, more severe case especially Oshma's score 1 tended to increase each year.

The 2nd: About 30 to 40 percent of users required some intensive medical cares. Therefore, medical and/or habilitation stuffs were necessary to arrange.

The 3rd: Duration of utilization was quite long (mean: over 10 years), which through the life-stage such as child to adult. Consecutive care and support from child to adult are important in SMID.

The 4th: Users were quite various as to the age and degree of handicaps, so daily activity and care program should be also diversity. Therefore, many welfare and education stuffs were also necessary to arrange.

The day-care services with medical and welfare stuffs (various kinds of specialist) are important and necessary for general supports of SMID living at home.

<Slide 14>

Support system for SMID living at home is illustrated in this slide. Day-care service for daily activity, short-stay service for respite, and home-help service are regarded as main supports. And, among these three services, day-care service may be core on the point of being able to ordinary management.

<Slide 15> CONCLUSION

Day-care services which can provide medical care are very important and necessary for the welfare of persons with SMID living at home. These centers are useful for their daily activities, maintenance of general health, developmental habilitation, and also education.

A review of services to persons with severe motor and intellectual disabilities in five day-care centers over 23 years



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NISH

INTRODUCTION

Day-care service for persons with severe motor and intellectual disabilities (SMID) was established in 5 institutes in 1990.

Thereafter, number of institutes were gradually increased, and being now more than 300 institutes, in Japan.

About 6,000 persons with SMID utilized these institutes for medical and welfare services.

These day-care services may contribute to keep stable health and daily-activities for persons with SMID living at home.

A-type: 15 persons/day, with medical care and transport system
B-type: 5 persons/day, mainly for regional service

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OBJECT

Day-care service restricted to SMID (Tuenjigyou) was started from 1990, and was continued for 23 years. In 2012, this service system was shifted to the new ones of divided into child and adult services and involved services to the other kinds of handicaps.

In this study, we reviewed the experiences of these 5 day-care centers since their inception. And, we want to clarify 1) a role of achievement and utility of these service for SMID living at home, 2) problems and difficulties on practice in these services, 3) what services being effective or better (specified to SMID)?

We wish to propose to the new system regarding the consequence of this study.

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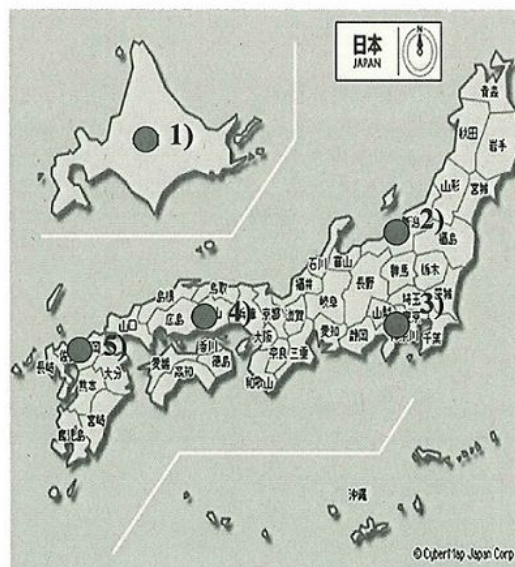
SUBJECT and METHOD

5 day-care centers

- 1) Hokkaido Ryoikuen
- 2) Nagaoka Ryoikuen
- 3) Yokohama Ryoiku center
- 4) Asahigawaso Ryoiku center
- 5) Hisayama Ryoiku center

Examination contents

- * Users profile (for 23 years)
degree of handicaps, medical care
- * State of using the centers
age at start and stoppage,
duration, turning points of using
- * Daily activity & care in the centers



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Users in 5 day-care centers over 23-year period

A-center: 100 persons (male 54, female 46)

B-center: 83 persons (male 39, female 44)

C-center: 282 persons (male 146, female 136)

D-center: 165 persons (male 94, female 71)

E-center: 152 persons (male 74, female 78)

total: 782 persons (male 407, female 375)

- Users rapidly increased just after the start of service, and being 2 or 3 holds of the fixed number (15 persons/day). It suggests that respective centers may cover the area with a population of 500 ~ 700 thousand.
- Transport (home ⇔ center) was extensive 20~100 km area.

NISH

Severity of handicaps (Oshima's score)

	A	B	C	D	E	total(%)
1,2,3,4	73(79)	74(89)	227(81)	165(95)	142(93)	672(86.8)
5,6,10,11	9	9	34	4	8	64
8,9,15,16	6	0	10	5	0	21
others	12	0	11	0	2	25

- SMID in narrow sense (Oshima: 1 to 4) occupied 79.3~94.5%. This was almost equal to the in-patients of SMID institutes.
- Severe cases of Oshima 1 tended to increase each year.

Brain injury: pre-natal 26.3%, peri-natal 51.2%, post-natal 22.0%

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Medical Care

	A	B	C	D	E	Total(%)
IMC*	10	16	16	13	10	65(8.3)
SIMC**	11	19	43	21	24	118(15.1)
total	21(21)	35(42)	59(21)	34(21)	34(22)	183(23.4)
Ventilator	7	5	13	5	8	38(4.9)
Tracheostomy	14	12	26	14	18	84(10.7)
Freq. suction	18	44	64	31	54	211(27.0)
Tube-feeding	18	10	77	38	56	229(29.3)

IMC*: cases with intensive medical care (Suzuki's score: over 25)

SIMC**: cases with semi-intensive medical care (score: 10 to 24)

* Cases with ventilator abruptly increased since 2008 (post-NICU?).

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Turning points of using services

	A	B	C	D	E	total(%)
Currently using (Group A)	41	37	140	76	59	353 (45.1)
Hospitalization (Group B)	21	27	41	10	24	123 (15.7)
Death while using (Group C)	12	14	35	23	24	115 (13.8)
Others	26	5	66	56	45	198 (25.3)

● Cases hospitalized to SMID institutes were slightly different between the centers (high in B-center, low in D-center).

* Others: stoppage of using caused by entrance into the school, removal, change to out-patient management, etc.

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Age at the start of using services (all cases)

	A	B	C	D	E	total(%)
< 6y	3	0	112	48	48	211(26.9)
6-12	15	5	37	17	25	99(12.7)
12-18	30	8	59	27	20	144(18.4)
18-24	25	46	58	54	38	221(28.3)
24-30	7	12	8	8	8	43(5.5)
30y <	15	12	8	11	13	59(7.5)
mean age	19.7	22.4	11.3	14.7	13.7	

- Age at the start of using was widely varied 1 to 59 years, and showed two peaks at pre-school age and post-graduate age.

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Duration of utilization 1 (Group A: 353 cases)

	A	B	C	D	E	total(%)	
Start age	18.8	20.8	11.9	15.2	15.6	15.0	
Duration	13.1	12.3	7.8	11.3	10.4	10.2	
Ex. age	31.9	32.9	20.5	26.5	25.9		
duration	< 5y	12	14	47	18	16	107(30.3)
	5-10	6	3	59	20	13	101(28.6)
	10-15	7	3	10	14	10	44(12.5)
	15y <	18	17	24	14	20	103(29.2)

- Mean duration of utilization was over 10 years. It is remarkable that about 30% of cases continued to use for over 15 years (52 cases: continued for 23 years).

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Duration of utilization 2 (Group B: 123 cases)

	A	B	C	D	E	total(%)	
Start age	25.0	25.6	16.8	18.6	23.5	21.6	
Duration	8.9	13.0	7.9	7.7	8.2	9.2	
Hosp. age	33.9	38.3	24.7	26.3	31.7		
duration	< 5ys	8	7	18	5	9	47(38.2)
	5-10	3	1	7	0	3	14(11.4)
	10-15	6	4	10	3	10	33(26.8)
	15ys <	4	15	6	2	2	29(23.6)

- Starting age was slightly high compared with Group A. and duration of utilization was about 9 years.
Hospitalization: 5 (7.7%) in IMC, and 13 (11.0%) in SIMC *NISH*

Duration of utilization 3 (Group C: 115 cases)

	A	B	C	D	E	total(%)	
Start age	15.4	20.9	11.3	17.3	13.3	13.8	
Duration	9.5	11.6	4.9	4.9	6.3	6.2	
Death age	24.9	32.5	16.3	22.2	19.6		
duration	< 5ys	4	4	21	16	12	57(49.6)
	5-10	3	1	7	5	4	20(17.4)
	10-15	1	4	4	1	5	15(13.0)
	15ys <	3	5	2	2	3	15(13.0)

- Starting age was slightly low, and duration was 5 to 10 years.
About half of cases died within 5 years utilization.
Incidence of death in IMC was 23.0% (slightly high). *NISH*

Daily activities and cares

Individual program was designed for their quality of life.

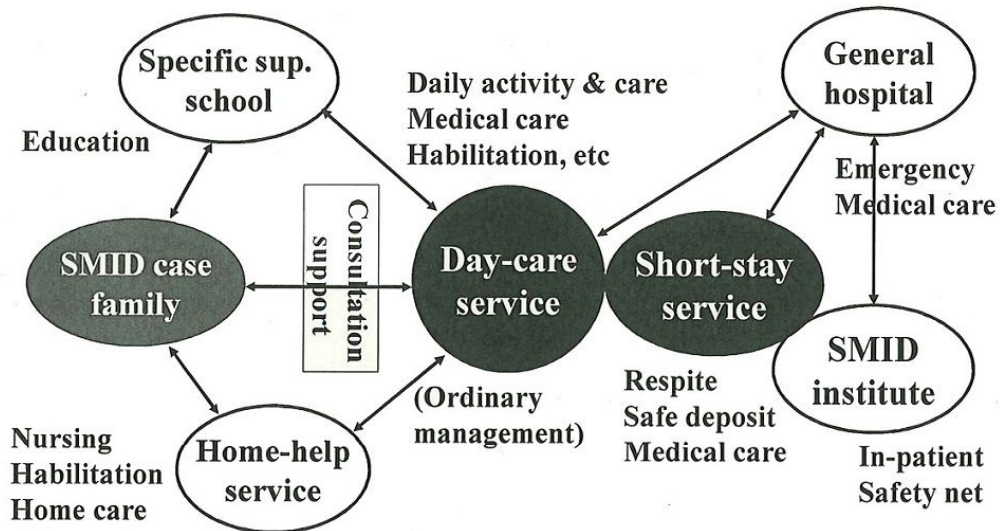
- **Activities corresponding to their handicaps**
Severe cases: Input of various senses (sensory, auditory, visual, and vestibular) was done for main activities.
Habilitation (PT, OT, and ST) was also regularly performed.
Mild cases: dynamic activities (include outside and production works etc) was done for individual developmental level.
- **Daily care**
Almost all cases was necessary for many supports of daily life, such as body change, eating, excretion, body cleaning, etc.
- * These daily activities and cares produce regularity of daily life cycle which may be directly related to their QOL.

NISH

SUMMARY

- @ Needs for day-care services (specified to SMID) were many and strong, so the center always received 2 or 3 holds persons. And, more severe cases may be further increasing.
- @ About 30-40% of users required some medical cares. Therefore, medical and/or training stuffs was necessary to arrange.
- @ Duration of utilization was quite long (mean over 10 years), which through the life-stage such as child to adult. Consecutive care and support from child to adult are important in SMID.
- @ Users were quite various as to age and degree of handicaps, so daily activity and care program should be also diversity. Therefore, many welfare and education stuffs were also necessary to arrange.
- * The day-care services with medical and welfare stuffs (various kinds of specialist) are important and necessary for general supports of SMID living at home

Support system for SMID living at home



NISH

CONCLUSION

Day-care services which can provide medical care are very important and necessary for the welfare of persons with SMID living at home.

These centers are useful for their daily activities, maintenance of general health, developmental habilitation, and also education.

NISH

(2) Time study on the care for SMID at a day-care center

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Background: Improvements in life prognosis of NICU patients and SMID patients have led to increased number of SMID, especially SMID-medical care dependent group (SMID-MCDG) patients cared at home. To assess the present status of SMID care we performed a time study at a day-care center for SMID patients.

Method:

Eleven day care center staff members (3 nurses, 1 nurse's aide, 4 child counselors, 2 kindergarten teachers, and 1 physical therapist) were the subjects.

The center had a capacity for 15 patients at one time, with 36 regular users. The average age of the patients was 18.9 years with 4 SMID-MCDG patients. Most of the users were suffering from cerebral palsy.

Each minute of work for each staff members for 3 days (8 hours each day) was recorded on February 26, 27, and 28, 2008. The content of the work was divided into of 6 work codes: A (life support or care management), B (life care), C (medical care), D, (social participation), E (community life support), and F (others).

The activities of staff members were compiled and analyzed via EXCEL in order to assess the burden of the care-giver at home.

Results:

Average care time for one user was 139.0 minutes/day (A: 3.7, B: 79.7, C: 11.9, D: 43.8, E: 0, and F: 0.1 minutes). Total work time was 3337.0 minutes/day. Care was provided by child counselors, nurses, kindergarten teachers, the nurse's aide, and the physical therapist in this order.

Staff also engaged in 2578.5 minutes of common work such as transporting patients and preparing for activities.

Implications:

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 patients' conditions. This will contribute to improved life prognosis of SMID patients.

Time study on the care of individuals
with severe motor and intellectual
disabilities at a day-care center

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Background Improvements in life expectancy of neonatal intensive care (NICU) patients and patients with severe motor and intellectual disabilities (SMID ≡ PIMD) have led to increased numbers of persons with SMID cared for at home, including those who are dependent on medical care. To assess the present status of SMID care we performed a time study at a day-care center for persons with SMID.

Method Eleven day care center staff members were the subjects. The center had a capacity for 15 individuals at one time, with 36 regular users. The average age of the clients was 18.9 years with 4 who were dependent on medical care. Most of the clients were suffering from cerebral palsy. Each minute of work for each staff members for 3 days (8 hours each day) was recorded on February 26, 27, and 28, 2009.

subject

ID			staff (occupation)
1	10	20	O (nurses' aid)
2	11	21	H (child counselor)
3	12	22	M (child counselor)
4	13	23	B (child counselor)
5	14	24	K (kindergarten teacher)
6	15	25	S (nurse)
7	16	26	Y (nurse)
8	19	29	Fk (kindergarten teacher)
9			I (nurse)
17	27		F (PT)
18	28		Ft (child counselor)

29 work day

Method

The content of the work was divided into of 6 work codes:

A : life support or care management

B : life care

C : medical care

D : social participation support

E : community life support

F : others

The activities of staff members were compiled and analyzed via EXCEL in order to assess the burden of the care-giver at home.

Method

Work code

A: life support or care management	C: medical care
A4: information exchange between staffs	C1: medication
A7: making record of the time of care	C2, 3: suction of sputum
A8: making individual care plan	C4, 5: tube feeding assistance
B: life care	C8, 9: treatment
B1, 2, 3: patient hygiene, grooming	C10: examination/measurement
B4, 5, 6: clothes changing	C11: physician support
B7: bathing	C14: hydration
B8: toilet support	C16: infection prevention
B9, 10, 11: meal assistance	C20: training (non-professional)
B12, 13, 14: posture change	D: social participation support
B15, 16, 17: transfer to/from wheel chair	D1, 2, 3, 4: recreation (group)
B18, 19, 20: patient transfer	D5, 6, 7, 8: recreation (individual)
B21, 22, 23: posture support	D16: transportation service
B30, 31, 32: temperature taking	E: community life support
B33, 34, 35: indirect patient assistance	F: others
B36, 37, 38: environmental organization	F1: cleaning task, conference
B40: bed/linen organization	F2: break, meal
B41: laundry	
B42: organization of patient goods	
B45, 46: communication	
B49: supervision	
B50: others	

For each code 2 numbers indicate preparation or cleanup and practice, 3 numbers indicate supervision, stimulative speech, and practice, 4 numbers indicate preparation, practice, cleanup, and others.

<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)

	21	22	23	24	25
	20	13	14	15	16
	19	12	7	8	9
	18	11	6	3	4
	17	10	5	2	1
	Able to run	Able to walk	Able to walk with support	Able to sit	Bed ridden

(Oshima, 1971)

Underlining disease should be childhood onset.

Result

Care of client 1-1

Oshima's Classification 5

staff ID	occupation	supervision	stimulative speech	direct care	work content	work code	time of the beginning	work time (min.)
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			

Result

Care of client 1-2

staff ID	occupation	supervision	stimulative speech	direct care	work content	work code	time of the beginning	work time (min.)
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
2	child counselor		1		temperature taking	B32		
1	nurses' aid		1		recreation (individual)	D6	10:30	3.0
1	nurses' aid		1		read parent note	D6	10:41	1.0
5	kindergarten teacher		1	1	toilet support	B8	10:43	5.0
1	nurses' aid		1		recreation (card play)	D2	10:49	1.0
2	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	Oshima's Classification 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		
		7	nurse	1			departure	B49	9:33	3
				1				D16		
						1	suction of the trachea	C2	~	
						1		C3		
						1		D16		
						1		C2		
						1		C3	9:35	
						1		C16		
				1	1	1	put a cap on the head	B49	9:37	
1	1			1	B46					
1	1			1	D16					
1				1	temperature taking & supervision	B49	9:38			
1				1		D16				
1				1		B30				
1		1	B49							
1		1	B31							
1		1		B32	9:39					

<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		supervision during transportation	B32	9:40	7
					1			B46		
					1			D16		
				1				B49		
				1				D16		
				1				B49		
				1				D16		
					1			D16		
					1			B49		
					1			B46		
				1				B49		
				1				D16		
				1	1			D16		
				1	1			B49		
				1	1			B46		
				1			D16			
				1			B49			
						1	suction of the trachea	D16	9:47	
						1		C2		
						1		C3		
						1		D16		
						1		C2	~	
						1		C3		
1			supervision	B49	9:48					
1					D16	9:52				
		1			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	1	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	588.6	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

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

Background The system of tuenjigyou (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 tuenjigyou. 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 tuenjigyou 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, cocking, 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 SM

ID.

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

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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 daily 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.