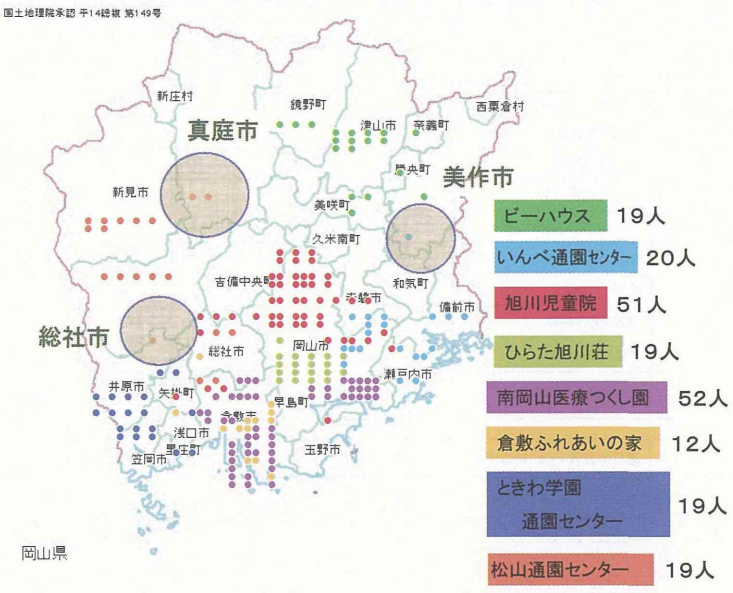


図3　重症児通園を利用されているケースの市町村別地図
（岡山県：人口約200万人）

図4　生活介護事業所で、重症児を対象にしている事業所
（岡山県：人口約200万人）

表1　岡山県下の重症児者日中活動事業（H26.1月現在）

	施設名	定員（人）	児童発達支援	医療型児童発達支援	生活介護	放課後児童デイ	備　考
重症児通園	旭川児童院通園ｾﾝﾀｰ	20	○		○	○	
	南岡山医療ｾﾝﾀｰ	15		○	○	○	
	松山通園ｾﾝﾀｰ	5	○		○	○	
	いんべ通園ｾﾝﾀｰ	5	○		○	○	
	ひらた旭川荘通園ｾﾝﾀｰ	5	○		○	○	
	ときわ通園ｾﾝﾀｰ	20			○		
	ビイーハウス	5	○		○	○	
	倉敷くすのき園	6		○	○	○	
	すまいるハウス	5	○		○		
	真庭療育センター	5	○		○	○	H26年4月開設
その他	瀬戸障害者ﾃﾞｲｾﾝﾀｰなずな	20			○		
	すまいる，いちにのさん	34			○		
	中山道ﾃﾞｲｻｰﾋﾞｽｾﾝﾀｰ	20			○		
	ﾃﾞｲｾﾝﾀｰなずな玉柏	25			○		H25年4月開設
	すまいるⅡ	25			○		H26年2月開設
	土田の里　花音	8			○		H25年7月開設

Ⅱ－８．国際学会での発表

（１）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」

③にこにこハウス医療福祉センター施設長　水戸 敬

「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」

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

Tohru KONISHI [1], Nobuyoshi MIYAZAKI [2]
1 Nagaoka Ryoikuen, Niigata, Japan; 2 Hisayama-Ryoikuen Center for SMID, Fukuoka, Japan

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, Nagaoka 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 tented 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 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 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

Tohru KONISHI 1
Nobuyoshi MIYAZAKI 2

1 Nagaoka-Ryoikuen, Niigata, Japan
2 Hisayama-Ryoiku Center for SMID, Fukuoka, Japan

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

NISH

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.

NISH

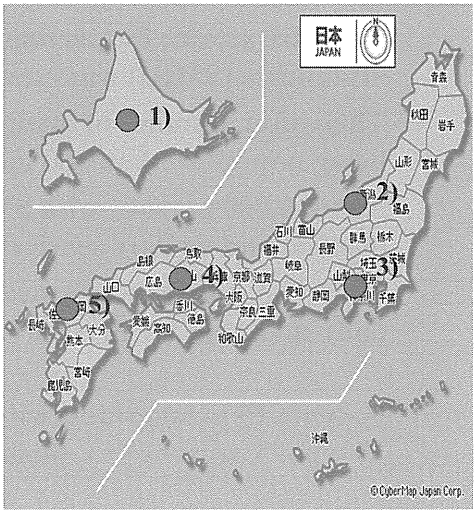
SUBJECT and METHOD

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**



NISH

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 (male146, female136)
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%

NISH

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?).

NISH

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.

NISH

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.

NISH

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).

NISH

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.**

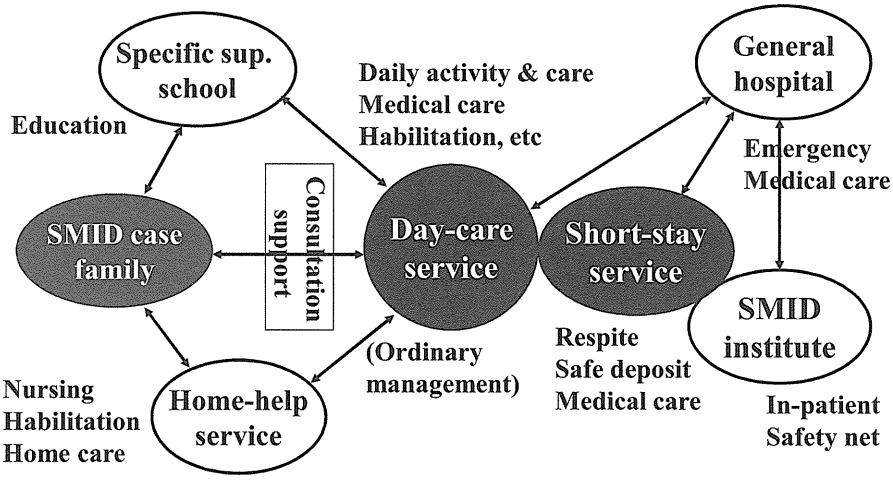
@ **About 30-40% of users required some medical cares. Therefore, medical and/or training stuffs was necessary to arrange.**

@ **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

Tadashi Matsubasa, M.D., Ph.D.
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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

Tadashi MATSUBASA
Kumamoto University, Kumamoto, JAPAN

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

Table 2. Main 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	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.	
	B45, 46: communication		
	B49: supervision		
	B50: others		