# 応援宣言シート

写 真

さんへ

私は、可能は範囲において、あなたの社会参加を応援します。あなたが地域で生き生きと生活できるように願っています。

私が具体的にお手伝いできることは以下の通りです。

職務としてお手伝いできること

支援機関名

職名

ボランティアとしてお手伝いできること

氏名

連絡先 〒

TEL FAX e-mail

宣言日 年 月 日

Ⅱ. 研究成果の刊行に関する一覧表

不严重心	<del>,</del>				<del>,</del>
発表者氏名	論文タイトル名	発表誌名	巻号	ページ	出版年
Inagaki M	An assessment of social	Proceedings of		775-	2003
Horiguchi T	networks between	16th Asian		780	!
Kaga M	facilities and specialists	Conference			
	for persons with	on Mental	1		
	intellectual disabilities	Retardation			
	in Japanese physicians.				
Horiguchi T	An assessment of	Proceedings of		783-	2003
Inagaki M	utilization of social	16th Asian		788	
Kaga M	support services for	Conference on			
	persons with intellectual	Mental			
	disabilities in Japanese	Retardation			
	physicians.				
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Terakawa S	problems of health	16th Asian			
Mizoguchi Y	examination for infants	Conference on			
	in Japan.	Mental			
		Retardation			
Tanaka A	Causes of Institutional	Proceedings of		547-	2003
Hosokawa T	Residence or	16th Asian		555	
Inagaki M	Employment among	Conference on			
	Graduates from School	Mental			
	for the Intellectually	Retardation			
	Disabled, Analyzed with				
	the ICF.				
Hayashi T	Actual condition of use	Proceedings of		781-	2003
Kido K	of anti-psychotic drugs	16th Asian		782	
Nakamura H	in institute for people	Conference on			
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· · · · · · · · · · · · · · · · · · ·	的支援サービスの利用				
	状況について	<u> </u>		L	

田中恭子,	精神遅滞の医学的診断	脳と発達	36	224-229	2004
堀口寿広,	と療育連携に関する研	[	<u> </u>		
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加 我 牧 子.	おける精神遅滞児の医				
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木戸久美	知的障害をもつ子ども	発達障害研究	26	38-51	2004
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美, 芳 原 達	較一.				:
也.					
林 隆,	知的障害者の行動障害	山口県立大学	8	1-4	2004
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	ている精神科関連薬剤		·		
	  に関する調査.				ı
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Inagaki M.	for the persons with	International			٠.
	intellectual disability,	Congress of	,		
	analyzed with the ICF	Psychology			

### Ⅲ. 研究成果の刊行物・別刷り

## An Assessment of Social Networks Between Facilities and Specialists for Persons with Intellectual Disabilities in Japanese Psysicians

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### Introduction

Social networks deserved for persons with intellectual disabilities (ID, mental retardation: MR) include various caring services, facilities, and health care specialists; and therefore, the networks per se have interpersonal aspects. Since specialists especially use the networks and collaborate with other specialists to support persons with ID for their full participation, knowledge and experience of a specialist may affect the "quality" of service in some cases<sup>2)</sup>. Thus we assessed the social (inter-facilitative and interpersonal) networks for persons with ID utilized by Japanese physicians specialized in pediatric neurology that numbers of persons with ID consult for the first time.

### Methods

Details of methods re-appear in another work by us. Randomly selected 289 member physicians of Japanese Society of Child Neurology received a mail-in questionnaire. Assessment inquired following questions: (a) how many persons used each social service, (b) which facilities did you contact (and/or visited) with in a past year, (c) how many persons used community care services and (d) which health care specialists did you cooperated with in a past year. The questionnaire asked personal data (except for name of him/herself and affiliation), and welcomed free comments of respondents.

Each question of (b) had choices "Yes, I have cooperated with it", "No, I have never cooperated, but I know it", and "I have no knowledge of it"; and more, item (b) questioned visit(s) to each facility as well ("I have worked there", "I have visited", "I have never visited"). Item (d) had choices "I have cooperated with them", "I have never cooperated", "I don't know about the specialist".

Our questionnaire defined cooperation with other specialists and/or facilities as various direct/indirect activities including refer or consultation of person(s), meeting(s), and working at the facility (including part-time job).

### Results

One-hundred and thirteen (39.1%) physicians answered our questionnaire. They contained 86 (76.1%) males and 18 (15.9%) females, and about a half of them had 20-30 year carriers. We present detailed information of our respondents in another report.

### (1) Network between facilities

Half or more of respondents had networks with Facilities and Day care centers for children (with MR and motional disabilities), Hospital-homes for children with severe mental and physical disabilities (severe motor and intellectual disabilities: SMID), Child guidance centers, Public health centers, and Welfare bureaus of city office. On the other hand, half or more did not have connection with Welfare factories, Hostels for employees with MR, Housings reserved for people with MR, Group homes, Counseling centers for the rehabilitation of people with MR, Vocational centers, Human resources development centers for the disabled, Regional social insurance bureaus,

Community centers for children, and Centers for regional welfare right protection programs. Summed answers of "I did not have networks with it" and "I have no knowledge of it" for Factories (88.5%), Hostels (91.2%), Group homes (85.0%), Counseling offices (82.2%), Vocational centers for persons with disabilities (87.6%), Human resources development centers (90.2%), Social insurance bureaus (81.4%), Community centers (85.8%), and Centers for right protection (96.5%) exceeded 80%. (Table 1)

Table 1: Number (%) of persons who had networks with and visited the facilities in a past year

Table 1: Number (%) of persons who had networks with and visited the facilities in a past year										
Had	No	Not	No	Work-	Been	Never	No			
nets	nets	know	info.	ed		been	info.			
67	24	0	22	6	36	32	- 35			
(59.3)	(21.2)	(0.0)	(19.5)	(5.3)	(31.9)	(28.3)	(31.0)			
77	18	0	18	15	36	32	29			
(52.5)	(15.9)	(0.0)	(15.9)	(13.3)	(31.9)	(28.3)	(25.7)			
80	10	0	23	34	34	22	22			
(70.8)	(8.8)	(0.0)	(20.4)	(30.1)	(30.1)	(19.5)	(19.5)_			
69	21	1	22	18	35	33	26			
(61.1)	(18.6)	(0.9)	(19.5)	(15.9)	(31.0)	(29.2)	(23.0)			
79	14	0	20	16	36	31	29			
(69.9)	(12.4)	(0.0)	(17.7)	(14.2)	(31.9)	(27.4)	(25.7)			
31	54	7	21	0	10	58	44			
(27.4)	(47.8)	(6.2)	(18.6)	(0.0)	(8.8)	(51.3)	(38.9)			
23	54	10	26	1	3	65	43			
(20.4)	(47.8)	(8.8)	(23.0)	(0.9)	(2.7)	(57.5)	(38.1)			
		, ,								
44	40	7	22	2	12	60	38			
(38.9)	(35.4)	(6.2)	(19.5)	(1.8)	(10.6)	(53.1)	(33.6)			
44	45	3	21	2	17	55	38			
(38.9)	(39.8)	(2.7)	(18.6)	(1.8)	(15.0)	(48.7)	(33.6)			
13	64	7	29	0	9	62	41			
(11.5)	(56.6)	(6.2)	(25.7)	(0.0)	(8.0)	(54.9)	(36.3)			
42	50	1	20	0	18	54	40			
(37.2)	(44.2)	(0.9)	(17.7)	(0.0)	(15.9)	(47.8)	(35.4)			
10	68	12	23	0	1	70	42			
(8.8)	(60.2)	(10.6)	(20.4)	(0.0)	(0.9)	(61.9)	(37.2)			
10	70	10	23	0	2	68	43			
(8.8)	(61.9)	(8.8)	(20.4)	(0.0)	(1.8)	(60.2)	(38.1)			
16	67	7	22	0	6	67	40			
(14.2)	(59.3)	(6.2)	(19.5)	(0.0)	(5.3)	(59.3)	(35.4)			
56	34	1	22	0	13	60	40			
(49.6)	(30.1)	(0.9)	(19.5)	(0.0)	(11.5)	(53.1)	(35.4)			
20	57	12	24	0	6	62	45			
(17.7)	(50.4)	(10.6)	(21.2)	(0.0)	(5.3)	(54.9)	(39.8)			
	Had nets 67 (59.3) 77 (52.5) 80 (70.8) 69 (61.1) 79 (69.9) 31 (27.4) 23 (20.4) 44 (38.9) 44 (38.9) 13 (11.5) 42 (37.2) 10 (8.8) 10 (8.8) 16 (14.2) 56 (49.6) 20	Had nets         No nets           67         24           (59.3)         (21.2)           77         18           (52.5)         (15.9)           80         10           (70.8)         (8.8)           69         21           (61.1)         (18.6)           79         14           (69.9)         (12.4)           31         54           (27.4)         (47.8)           23         54           (20.4)         (47.8)           44         40           (38.9)         (35.4)           44         45           (38.9)         (39.8)           13         64           (11.5)         (56.6)           42         50           (37.2)         (44.2)           10         68           (8.8)         (60.2)           10         70           (8.8)         (61.9)           16         67           (14.2)         (59.3)           56         34           (49.6)         (30.1)           20         57	Had nets         No nets         Not know           67         24         0           (59.3)         (21.2)         (0.0)           77         18         0           (52.5)         (15.9)         (0.0)           80         10         0           (70.8)         (8.8)         (0.0)           69         21         1           (61.1)         (18.6)         (0.9)           79         14         0           (69.9)         (12.4)         (0.0)           31         54         7           (27.4)         (47.8)         (8.8)           (20.4)         (47.8)         (8.8)           44         40         7           (38.9)         (35.4)         (6.2)           44         45         3           (38.9)         (35.4)         (6.2)           42         50         1           (37.2)         (44.2)         (0.9)           10         68         12           (8.8)         (60.2)         (10.6)           10         70         10           (8.8)         (61.9)         (8.8)	Had nets         No nets         Not know info.           67         24         0         22           (59.3)         (21.2)         (0.0)         (19.5)           77         18         0         18           (52.5)         (15.9)         (0.0)         (15.9)           80         10         0         23           (70.8)         (8.8)         (0.0)         (20.4)           69         21         1         22           (61.1)         (18.6)         (0.9)         (19.5)           79         14         0         20           (69.9)         (12.4)         (0.0)         (17.7)           31         54         7         21           (27.4)         (47.8)         (6.2)         (18.6)           23         54         10         26           (20.4)         (47.8)         (8.8)         (23.0)           44         40         7         22           (38.9)         (35.4)         (6.2)         (19.5)           44         45         3         21           (38.9)         (39.8)         (2.7)         (18.6)           13	Had nets         No nets         No know info.         Worked           67         24         0         22         6           (59.3)         (21.2)         (0.0)         (19.5)         (5.3)           77         18         0         18         15           (52.5)         (15.9)         (0.0)         (15.9)         (13.3)           80         10         0         23         34           (70.8)         (8.8)         (0.0)         (20.4)         (30.1)           69         21         1         22         18           (61.1)         (18.6)         (0.9)         (19.5)         (15.9)           79         14         0         20         16           (69.9)         (12.4)         (0.0)         (17.7)         (14.2)           31         54         7         21         0           (69.9)         (12.4)         (0.0)         (17.7)         (14.2)           31         54         7         21         0           (27.4)         (47.8)         (8.8)         (23.0)         (0.9)           44         40         7         22         2	Had nets         No nets         Not know info.         Worked         Been ed           67         24         0         22         6         36           (59.3)         (21.2)         (0.0)         (19.5)         (5.3)         (31.9)           77         18         0         18         15         36           (52.5)         (15.9)         (0.0)         (15.9)         (13.3)         (31.9)           80         10         0         23         34         34           (70.8)         (8.8)         (0.0)         (20.4)         (30.1)         (30.1)           69         21         1         22         18         35           (61.1)         (18.6)         (0.9)         (19.5)         (15.9)         (31.0)           79         14         0         20         16         36           (69.9)         (12.4)         (0.0)         (17.7)         (14.2)         (31.9)           31         54         7         21         0         10           (27.4)         (47.8)         (8.8)         (23.0)         (0.9)         (2.7)           44         40         7         22 <td< td=""><td>Had nets         No nets         Not nets         No info.         Worked ed         Been been been been           67         24         0         22         6         36         32           (59.3)         (21.2)         (0.0)         (19.5)         (5.3)         (31.9)         (28.3)           77         18         0         18         15         36         32           (52.5)         (15.9)         (0.0)         (15.9)         (13.3)         (31.9)         (28.3)           80         10         0         23         34         34         22           (70.8)         (8.8)         (0.0)         (20.4)         (30.1)         (30.1)         (19.5)           69         21         1         22         18         35         33           (61.1)         (18.6)         (0.9)         (19.5)         (15.9)         (31.0)         (29.2)           79         14         0         20         16         36         31           (69.9)         (12.4)         (0.0)         (17.7)         (14.2)         (31.9)         (27.4)           31         54         7         21         0         10         58</td></td<>	Had nets         No nets         Not nets         No info.         Worked ed         Been been been been           67         24         0         22         6         36         32           (59.3)         (21.2)         (0.0)         (19.5)         (5.3)         (31.9)         (28.3)           77         18         0         18         15         36         32           (52.5)         (15.9)         (0.0)         (15.9)         (13.3)         (31.9)         (28.3)           80         10         0         23         34         34         22           (70.8)         (8.8)         (0.0)         (20.4)         (30.1)         (30.1)         (19.5)           69         21         1         22         18         35         33           (61.1)         (18.6)         (0.9)         (19.5)         (15.9)         (31.0)         (29.2)           79         14         0         20         16         36         31           (69.9)         (12.4)         (0.0)         (17.7)         (14.2)         (31.9)         (27.4)           31         54         7         21         0         10         58			

(continued)

Table 1 (continued)

	Had	No	Not	No	Work-	Been	Never	No
	nets	nets	know	info.	ed		been	info.
Child guidance centers	92	8	0	13	15	31	34	33
	(81.4)	(7.1)	(0.0)	(11.5)	(13.3)	(27.4)	(30.1)	(29.2)
Educational counseling office	55	29	9	20	5	24	44	40
	(48.7)	(25.7)	(8.0)	(17.7)	(4.4)	(21.2)	(38.9)	(35.4)
Vocational centers	14	66	9	24	1	4	62	46
	(12.4)	(58.4)	(8.0)	(21.2)	(0.9)	(3.5)	(54.9)	(40.7)
Human resources development	11	70	8	24	1	2	64	46
centers for the disabled	(9.7)	(61.9)	(7.1)	(21.2)	(0.9)	(1.8)	(56.6)	(40.7)
Public health center	91	6	0	16	26	41	19	27
	(80.5)	(5.3)	(0.0)	(14.2)	(23.0)	(36.3)	(16.8)	(23.9)
Welfare bureaus of city office	81	15	1	16	7	22	47	37
	(71.7)	(13.3)	(0.9)	(14.2)	(6.2)	(19.5)	(41.6)	(32.7)
Council of Social Welfare	39	50	5	19	3	14	55	41
	(34.5)	(44.2)	(4.4)	(16.8)	(2.7)	(12.4)	(48.7)	(36.3)
Regional social insurance	21	63	6	23	0	4	66	43
bureau	(18.6)	(55.8)	(5.3)	(20.4)	(0.0)	(3.5)	(58.4)	(38.1)
Mental health and Welfare	26	53	10	24	0	12	61	40
center	(23.0)	(46.9)	(8.8)	(21.2)	(0.0)	(10.6)	(54.0)	(35.4)
Community center for children	16	66	7	24	2	17	51	43
	(14.2)	(58.4)	(6.2)	(21.2)	(1.8)	(15.0)	(45.1)	(38.1)
Centers for regional welfare	4	60	23	26	0	2	63	48
right protection programs	(3.5)	(53.1)	(20.4)	(23.0)	(0.0)	(1.8)	(55.8)	(42.5)
Other(s)	28	23	7	55	0	6	41	66
	(24.8)	(20.4)	(6.2)	(48.7)	(0.0)	(5.3)	(36.3)	(58.4)

Male physicians answered "I had networks with Public health center" more frequently than females (Fisher's exact p=0.0007). Physicians with shorter carrier answered more frequently "no networks" with Sheltered workshops ( $\chi^2(df=12)=39.2$ , p<0.0001) and Public health center ( $\chi^2(df=6)=17.9$ , p=0.007) compared to more experienced physicians.

Averaged number of cooperated facilities for each physician was  $10.3~(\pm 6.5)$ , and patients in ages 3-7 (12.0 facilities in mean) and 7-12 (12.6 facilities) years old had more facilities compared to those in ages 12-15 (5.5 facilities). (Kruskal-Wallis p=0.002) And more, numbers of cooperated facilities correlated with numbers of patients with MR (Kendall  $\tau = 0.35$ , p<0.0001), autism (=0.37, p<0.0001), cerebral palsy (=0.28, p<0.0001), SMID (=0.26, p=0.0003), speech delay (=0.21, =0.002), motor delay (=0.23, p=0.003), and metabolic diseases (=0.25, p=0.001).

Twenty or more physicians had worked and/or visited Hospital-homes for SMID and Public health center, and 30 or more visited Facilities and Day-cares for children and Public health center. Half or more had not visited Facilities for autistic children and emotionally disturbed children, Rehabilitation facilities, Welfare factories, Hostels, Group-homes, Welfare offices, Counseling centers, Vocational centers, Human resources development centers, Social insurance bureaus, Mental health centers, and Centers for right protection (Safeguard center of rights for handicaps).

Summed answers of "I have visited" and "I have worked" were more frequent for Hospital-homes for SMID in physicians working at university hospitals ( $\chi^2(df=14)=30.4$ , p=0.007). Physicians of hospitals (including university hospitals) gave more frequently answers "I have never visited Rehabilitation facilities" ( $\chi^2(df=14)=53.0$ , p<0.0001). And more, physicians cared patients mostly ages less than 12 years old frequently answered "I have never visited Rehabilitation facilities" ( $\chi^2(df=10)=44.7$ , p<0.0001).

Averaged number of facilities which respondents had worked or visited was 5.4 ( $\pm$ 5.0). That did not differ by gender, experience, affiliation, and age range of patients, but differed by conditions of patients including MR ( $\tau$ =0.22, p=0.002), autism ( $\tau$ =0.29, p<0.0001), and neuro-muscular diseases ( $\tau$ =0.20, p=0.007). Number of visited facilities in each respondent correlated with number of cooperated facilities ( $\tau$ =0.26, p<0.0001).

Table 2: Number (%) of persons who cooperated with the following specialist(s) in a past year

Specialists	Cooperated	Not	No	No info.
Specialists	Cooperated	cooperated	knowledge	110 1110.
Public health nurse (PHN) <sup>a</sup>	80 (70.8)	13 (11.5)	0 (0.0)	20 (17.7)
Physical therapist (PT) <sup>a</sup>	82 (72.6)	12 (10.6)	0 (0.0)	19 (16.8)
Occupational therapist (OT) <sup>a</sup>	79 (69.9)	14 (12.4)	0 (0.0)	20 (17.7)
Speech therapist (ST) <sup>a</sup>	72 (63.7)	19 (16.8)	1 (0.9)	21 (18.6)
Social worker (SW) <sup>a</sup>	78 (69.0)	15 (13.3)	0 (0.0)	20 (17.7)
Care worker (CW) <sup>a</sup>	27 (23.9)	57 (50.4)	3 (2.7)	26 (23.0)
Psychiatric social worker (PSW) <sup>a</sup>	22 (19.5)	57 (50.4)	7 (6.2)	27 (23.9)
Child welfare officer c (civil official of Child	(1 (5( ()	24 (21.2)	2 (19)	22 (20.4)
guidance center)	64 (56.6)	24 (21.2)	2 (1.8)	23 (20.4)
Welfare officer for people with MR c (civil				
official of Welfare office and Counseling	21 (18.6)	54 (47.8)	12 (10.6)	26 (23.0).
center)				
Care manager b	24 (21.2)	58 (51.3)	5 (4.4)	26 (23.0)
In-home helper b	29 (25.7)	58 (51.3)	2 (1.8)	24 (21.2)
Care assistant for ID <sup>e</sup>	13 (11.5)	49 (43.4)	24 (21.2)	27 (23.9)
Welfare volunteer and child welfare volunteer d	30 (26.5)	57 (50.4)	2 (1.8)	24 (21.2)
Counselors for people with MR d	13 (11.5)	60 (53.1)	11 (9.7)	29 (25.7)
Parents' society in hospital	41 (36.3)	44 (38.9)	1 (0.9)	27 (23.9)
Parents' society	56 (49.6)	33 (29.2)	2 (1.8)	22 (19.5)
Peers' society	38 (33.6)	45 (39.8)	4 (3.5)	26 (23.0)
Child counselor (at facilities) c	34 (30.1)	45 (39.8)	9 (8.0)	25 (22.1)
Kindergarten nurse <sup>a</sup>	70 (61.9)	18 (15.9)	2 (1.8)	23 (20.4)
Schoolteacher <sup>a</sup>	87 (77.0)	8 (7.1)	0 (0.0)	18 (15.9)
Psychologist <sup>e</sup>	82 (72.6)	12 (10.6)	0 (0.0)	19 (16.8)
Other(s)	0 (0.0)	9 (8.1)	1 (0.9)	102 (90.3)

Type of qualification in Japan: a national license, b national (city) certification, c appointment by nation, d commission by nation (city), c certification by private organization

### (2) Cooperation with other specialists

More than seventy percent of physicians cooperated with teachers of kindergarten and school as a consultant or reference of the children. Answers "I have never cooperated with" exceeded half of the respondent in Parent counselors, Care managers, In-home helpers, Care workers, Psychiatric social workers (PSW), and Welfare volunteers. Answers "I have no knowledge of the specialist" were most frequent for Care assistants. And therefore, provided answers other than "Cooperated" meant no cooperation, 80% or more physicians did not cooperate with Care assistants, Counselors for people with MR, Welfare officers, and PSW. (Table 2)

Number of specialists whom cooperated with in a past year by each respondent was 9.2 ( $\pm$ 5.9) in mean, and it correlated with number of patients with each condition as follows; MR ( $\tau$  =0.26, p=0.0001), autism ( $\tau$  =0.27, p=0.0001), cerebral palsy ( $\tau$  =0.24, p=0.0004), SMID ( $\tau$  =0.25, p=0.0003), motor delay ( $\tau$  =0.25, p=0.0009), and metabolic diseases ( $\tau$  =0.29, p=0.0002). Number of cooperated specialists correlated with numbers of social support services provided to patients ( $\tau$  =0.26, p<0.0001), community care services ( $\tau$  =0.50, p<0.0001), cooperated facilities ( $\tau$  =0.45, p<0.0001), and visited facilities ( $\tau$  =0.25, p=0.0001).

### (3) Free comments

Fifty-three (46.9%) respondents gave several comments. Grouping of their comments made 70 comments in total.

The most common indication (18 comments, 25.7%) was 'needs' for facilities or services including facilities for adults with ID and increase of benefits. Others were as follows; new support system for children with autism or mild developmental disorders (10 comments, 14.3%), cooperation for follow-up appropriate to each life stage (6 comments, 8.6%). At last, comments demanding somewhat reform of facilities and services counted 40 (57.1%) in total. On the other hand, 12 (17.1%) in total requested training or facilitate human resources (i.e. specialists) including coordinator of services and internship of university students. Five (7.1%) were requests for individual effort of each physician (e.g. "physicians should go up to the front line").

### Discussion

Cooperation with facilities for children with ID, SMID, and motional disabilities was frequent, though less frequent with residential or vocational facilities in the present physicians. Physicians working at hospitals or caring younger patients had neither worked nor visited rehabilitation facilities for ID adults. These findings might be accounted for by the following reasons; physicians caring younger ages had more networks between facilities, and few of pediatricians cared patients continuously after 18 years old. For satisfactory supports appropriate to life stages of every recipient, not only reported features of the facilities but also actual experience to see persons in every facilities would easily illustrate features of persons with ID in each age. Physicians could support the person with ID in longer period compared to civil officials of welfare services since more than 90% of them have a reshuffle every 3 years in Japan.

Interpersonal cooperation among specialists was frequent in therapists at hospital and schoolteachers and public health nurses out of hospital. Physicians worked with other specialists in facility for assessment of development, training, and rehabilitation of children; and out of facility for special education at kindergarten and school. On the other hand, physicians were less familiar with specialists of in-home (community) care. While many physicians considered parent's or peer's

society as one of supports at community, they need to have more information on other available regional systems including Counselors for people with MR (Parent counselor).

In table 2, we presented type of qualification of each specialist. Among less familiar specialists, Care manager is obtained by nurses or other workers; and Care assistant by advisors at nursery homes. Physicians often participate in training and education for these specialists, and therefore, they can improve their quality of cooperation through communication and exchange of knowledge and techniques between other specialists.

Assessment of demanding needs of physicians revealed their needs for specialists coordinating medical, educational, and social supports based upon comprehension on any information about a person with ID. Such a role like a 'conductor of concert' or 'mentor of the team' may correspond to specialists including social workers, PSWs, care managers, coordinators for support program for community-based education an care for children with disabilities, guide helpers, and in-home helpers. Thus we hope that more number of these specialists work at many facilities to attain full participation of persons with ID.

### Conclusion

For enriched social participation, supports of persons with ID appropriate to life styles of each person are necessary.

### Acknowledges

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### An Assessment of Utilization of Social Support Services for Persons with Intellectual Disabilities in Japanese Physicians

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### Introduction

The Ministry of Health, Labour and Welfare<sup>3)</sup> in 2000 counted 329,200 persons having intellectual disabilities (ID, mental retardation: MR) in Japan, and another report estimated more than 560 thousand. The government provides various medical and social, educational and financial supports for them. Health care specialists need to attain continuous and comprehensive supports for full-participation using such available services appropriate in each life stage<sup>1)</sup>. And therefore, we assessed in physicians provides of social (including medical, educational, and financial) support services deserved for persons with MR supplied by Japanese government.

### Methods

We randomly selected 289 member physicians of Japanese Society of Child Neurology including 189 committees and 100 regular members. We mailed our questionnaire including questions as follows: (a) how many recipients for each social service, (b) which facilities contacted (and/or visited) with, (c) how many recipients for each community care services and (d) which health care specialists cooperated. The questionnaire also asked personal data (i.e. (e) gender, (f) experience as a specialist, (g) affiliation, (h) number of outpatients cared for each disorder in a month, (i) age range of patients mostly cared and (j) age of an oldest patient). Every question (except (h)) reminded their experience in a past year. And more, the questionnaire welcomed free statements of respondents.

For each item of (a) and (c), question had choices "Yes, I have provided it", "No, I have never provided, but I know it", and "I have no knowledge of it". When they chose "Yes", they also filled number of the recipients.

We collected anonymous answers by mail from December in 2002 to January in 2003. In this article, we especially studied utilization of social and community care services.

### **Results**

One-hundred and thirteen (39.1%) physicians answered our questionnaire. They contained 86 (76.1%) males and 18 (15.9%) females, and about a half of them experienced 20-30 years. (Table 1)

Table 1: Experience year as a physician

years	Below 5	5-10	10-20	20-30	30-40	40 or more	No Info.
number	1	1	30	53	23	2	2
. (%)	(0.9)	(0.9)	(26.5)	(46.9)	(20.4)	(1.8)	(1.8)

They worked in university hospitals and other hospitals. (Table 2) These properties distributed with no statistical significance.

Averaged numbers of patients cared in a month was large in epilepsy, MR, and cerebral palsy (CP). (Table 3) Patients with epilepsy were the most at university hospitals (n=37, 91.8 persons in mean)

compared to clinics (n=10, 17.7 persons) (Kruskal-Wallis p=0.015).

Table 2: Affiliations

	Univ.	Nation.	Other	Office/	Facility	Facility	Facility	Other	No
	Hosp.	Hosp.	Hosp.	Clinic	for MR	for SMID	for adults	Other	Info.
number	41	9	22	12	1	10	1	14	3
(%)	(36.3)	(8.0)	(19.5)	(10.6)	(0.9)	(8.8)	(0.9)	(12.4)	(2.7)

Table 3: Mean number of patients for each condition

	MR	Autism	Epi	СР	SMID	Speech delay	Motor delay	Neuro- muscular	Meta- bolic	Other
Mean	43.4	12.9	72.8	23.8	21.5	18.8	15.9	12.1	3.6	39.7
(SD)	(56.0)	(14.7)	(83.1)	(28.8)	(31.5)	(27.2)	(18.8)	(37.6)	(6.6)	(44.2)

Age range of patients cared in a past year was most frequent in 3-7 years old. (Table 4) Patients in these ages were the most at 20 (52.6%) university hospitals (n=38) and 10 (47.6%) 'Other hospitals' (n=21). At clinics, patients aged under 3 were the most common ( $\chi^2$ (df=42)=75.9, p=0.001).

Whereas only 10 physicians cared many patients aged 18 or more, the oldest age was in mean  $41.6 \ (\pm 17.1)$  years old. Nine physicians had cared age 60s, 5 for 70s, 1 for 80s, and 3 for 90s. And therefore, 17 (15.0%) of them had cared patients aged 65 or more. The oldest age was smallest at 'Other hospitals' (28.5 years old in mean), and it was large at clinics (58.8 years old) (Kruskal-Wallis p<0.0001). Ages of patients differed by neither gender nor experience of a physician.

Table 4: Age(s) of the oldest patients cared in a past year

ĺ	Ages	Under 3	3-7	7-12	12-15	15-18	18 or more	No Info.
ĺ	number	24	45	19	4	1	10	8
	(%)	(21.2)	(39.8)	(16.8)	(3.5)	(0.9)	(8.8)	(7.1)

More than 70% of physicians provided supports for Medical aid program for specific chronic pediatric diseases, Allowance for children with special disabilities and Medical care benefits for psychiatric outpatients. (Table 5) Provided both choices "Yes, I have used" and "No, but I know the service" meant knowledge, our respondents had information of almost all of services but Provision of rehabilitative medical care for people with physical disabilities and potential physical disabilities.

Tables 6 and 7 showed relations of provides of individual service and number of recipients with each condition. Physicians who provided each service had significantly large number of recipients with particular condition as follows: Premature Medicine in SMID (Kruskal-Wallis p=0.005); Allowance for special disabilities in AD (p=0.002) and metabolic diseases (p=0.007); Rehabilitation medicine for adults in MR (p=0.0004), AD (p=0.007), CP (p=0.0002), SMID (p=0.0003), and metabolic (p=0.006); Medical benefits for disabilities in epilepsy (p=0.005); Medical benefits for psychiatry in MR (p=0.006) and epilepsy (p<0.0001); Prosthetic appliances in MR (p=0.0007), AD (p=0.001), CP (p=0.0005), and neuro-muscular (p=0.005); welfare allowance in MR (p=0.009), AD (p=0.003), epilepsy (p=0.008), CP (p=0.005), and neuro-muscular (p=0.007); Other allowance in AD

Table 5: "Have you provided the following services in a past year?"

ole 3. Have you provided the following services in	i a pasi your		· · · · · · · · · · · · · · · · · · ·	
Services	Yes	No	No know.	No info.
N. 1. 1	16	56	7	29
Medical care benefits for premature babies	(14.2%)	(49.6%)	(6.2%)	(25.7%)
Provision of rehabilitative medical care for	34	44	3	28
children with physical disabilities	(30.1%)	(38.9%)	(2.7%)	(24.8%)
Medical aid program for specific chronic	75	17	0	14
pediatric diseases	(66.4%)	(15.0%)	(0.0%)	(12.4%)
Allowance for children with special disabilities	58	20	6	18
(National)	(51.3%)	(17.7%)	(5.3%)	(15.9%)
Provision of rehabilitative medical care for	10	44	25	27
people with disabilities	(8.8%)	(38.9%)	(22.1%)	(23.9%)
Medical care benefits for persons with severe	29	35	17	24
disabilities	(25.7%)	(31.0%)	(15.0%)	(21.2%)
Madical conduction for the formula and the state of the s	80	12	3	10
Medical care benefits for psychiatric outpatients	(70.8%)	(10.6%)	(2.7%)	(8.8%)
Provision and repair of prosthetic appliances	65 ·	22	1	16
(e.g. wheel car, artificial limbs)	(57.5%)	(19.5%)	(0.9%)	(14.2%)
Welfare allowance for children with physical	49	29	9	18
disabilities	(43.4%)	(25.7%)	(8.0%)	(15.9%)
Allowance for single parent having child(ren)	24	33	24	26
with disabilities or other allowances	(21.2%)	(29.2%)	(21.2%)	(23.0%)
Disability basic pension	58	25	7	13
Disability basic pension	(51.3%)	(22.1%)	(6.2%)	(11.5%)
Other	. 0	6	2	101
Outo	(0.0%)	(5.3%)	(1.8%)	(89.4%)

Table 6: Mean number of recipients for each service in a physician (who provided the service)

Services	Mean (SD)
Premature medicine	9.1 (11.8)
Rehabilitation medicine for children	4.7 (6.0)
Medicine of chronic diseases	17.4 (31.8)
Allowance for special disabilities	30.3 (58.7)
Rehabilitation medicine for adults	6.7 (9.7)
Medical benefits for disabilities	29.4 (51.6)
Medical benefits for psychiatry	34.1 (55.4)
Prosthetic appliances	13.0 (20.5)
Welfare allowance for children	9.5 (11.6)
Other allowances	6.6 (8.2)
Pension	7.3 (6.1)
Other	0 (0.0)

Table 7: Relation between use of services and condition

	MR	AD	Epi	СР	SMID	Speech	Motor	Neuro	Meta-	Other
			1						Bolic	
Nursery medicine										
Reform for children					0					٠
Chronic diseases									•	
Benefit (National)		0							0	
Reform for adults	. O	0		0	0				O	
Medical expense		X	0							
Psychiatric Expense	О		0	X	X	X	X			
Medical Devices	0	0		0				0		
Benefit (City)		-				•				
Benefit for single		0								
Pension	0		О	0				О	О	
Other										

O: Number of recipients was significantly large in those who answered "Yes, I have provided it".

(p=0.006); Pension in MR (p=0.005), epilepsy (p=0.0006), CP (p=0.0003), neuro-muscular (p=0.008), and metabolic (p=0.0003) persons.

Number of services provided in a year for each physician was in mean 2.4 ( $\pm 2.2$ ), and they correlated with number of recipients having MR (Kendall  $\tau$  =0.33, p<0.0001), AD ( $\tau$  =0.26, p=0.0002), epilepsy ( $\tau$  =0.40, p<0.0001), CP ( $\tau$  =0.36, <0.0001), SMID ( $\tau$  =0.36, p<0.0001), speech delay ( $\tau$  =0.28, p=0.0001), delay in motor function ( $\tau$  =0.30, p<0.0001), neuro-muscular disorder ( $\tau$  =0.31, p<0.0001) and metabolic disease (0.34, p<0.0001).

As for community care services, they frequently provided Short-time stay service (i.e. Respite Care) and Provision of daily life appliances (e.g. toilet, bath, nebulizer) for severely handicapped people. Twenty percent or more physicians answered "I don't know such system" to Regional welfare right protection programs and optional Mutual insurance for accident (or medical expense) for persons with MR'. (Table 8) Of the services, they provided frequently Dental care for severe disabilities, Special education at kindergarten and Provision of daily life appliances. (Table 9)

Number of services provided in a year for each physician was in mean 2.4 ( $\pm 2.2$ ), and they correlated with number of recipients having metal retardation (Kendall  $\tau = 0.25$ , p=0.0002), autistic disorder ( $\tau = 0.28$ , p<0.0001), epilepsy ( $\tau = 0.28$ , p<0.0001), delay in motor function ( $\tau = 0.33$ , <0.0001), neuro- muscular disease ( $\tau = 0.32$ , p=0.007) and metabolic disease ( $\tau = 0.22$ , p=0.004).

X: Number of recipients was significantly large in those who answered "I have no knowledge about it".

Table 8: "Have you provided the following community care services in a past year?"

			ac- jour.	
Services	Yes	No	No knowledge	No Info.
Special education at nursery school	45 (39.8%)	29 (25.7%)	5 (4.4%)	24 (21.2%)
In-home help	26 (23.0%)	53 (46.9%)	3 (2.7%)	26 (23.0%)
Short-time stay	51 (45.1%)	30 (26.5%)	3 (2.7%)	22 (19.5%)
Provision of daily life appliances	49 (43.4%)	26 (23.0%)	8 (7.1%)	25 (22.1%)
Home-visit medicine (nursing) for SMID	15 (13.3%)	51 (45.1%)	16 (14.2%)	28 (24.8%)
Dental care for severe disabilities	25 (22.1%)	45 (39.8%)	11 (9.7%)	28 (24.8%)
Day care service	16 (14.2%)	53 (46.9%)	8 (7.1%)	29 (25.7%)
Home-visit care for severe CP	5 (4.4%)	58 (51.3%)	16 (14.2%)	31 (27.4%)
Guardianship	9 (8.0%)	53 (46.9%)	17 (15.0%)	31 (27.4%)
Regional welfare right protection programs	1 (0.9%)	51 (45.1%)	25 (22.1%)	33 (29.2%)
Mutual insurance	2 (1.8%)	52 (46.0%)	23 (20.4%)	33 (29.2%)
Other	0 (0.0%)	15 (13.3%)	5 (4.4%)	92 (81.4%)

Table 9: Mean number of recipients for each community care service in a physician

Services	Mean (SD)	
Special education	9.4 (11.4)	
In-home help	4.0 (6.0)	
Short-time stay	6.8 (14.8)	
Daily life appliances	7.9 (15.2)	
Home-visit medicine for SMID	3.1 (5.3)	
Dental care	12.8 (41.9)	
Day care service	6.1 (10.0)	
Home-visit care for severe CP	0.8 (1.0)	
Guardianship	0.9 (0.7)	
Right protection (Advocacy)	0.3 (0.5)	
Mutual insurance	0.8 (1.1)	
Other	0 (0.0)	

#### Discussion

Most physicians had provided various supports for ID (MR) persons regardless to both their affiliation and experience. Whereas provides of services depended on number of patients cared, number of recipients deserved for specific service differed by their condition. Although Medical benefit for psychiatry was most common, some physicians who cared mainly certain condition (e.g. CP, SMID) did not know such a service. The service was usually used by patients with epilepsy in pediatrics, and number of patients cared by each physician was largest in epilepsy.

On the other hand, physicians who provided various services seemed to have more number of MR and AD patients. Because the number of AD patients was relatively small, our finding suggests that care for AD possibly required various supports including financial benefits in childhood and aids by medical devices, and that other supports should be shared by other conditions.

Short-time stay was most common as community care since our respondents working in hospital

might usually consult their recipients to such facilities. Utilization of Daily life appliances was frequent; however, services for adults such as Home-visit and Day care were less common. And more, among social security systems, guarantee of rights of ID persons seemed less common. As an Advocacy system for community care, the Community social welfare right protection system started in 1999, includes contracts of management of personal finances (especially expense of care) and complaint procedures. In-home (i.e. community) care for full-participation of ID persons requires both medical and social aspects.

Anyway, services for adults (ages 18 or more) in general seemed less common; because more than 60% of our respondents cared children aged under 7 years old. A study of learning disorder (developmental dyslexia)<sup>2)</sup> found that parents found developmental problems of their children first around the age of 3 years old. Intervention and support at early childhood would have great magnitude. On the other hand, number of ID persons living in the community increases, and their ages advance<sup>4)</sup>. Thus physicians also should be familiar with community care services that will have greater demand in the near future.

### Conclusion

For the full-participation, knowledge of each service in specialists will enrich social supports appropriate to life styles of each person with ID.

### Acknowledges

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## The Present Situation and Problems of Health Examination for Infants in Japan

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### Present situation in Japan

Compulsory health examination for all infants and toddlers in Japan was implemented in 1979. This system has two main functions; one is for health professionals such as pediatricians to detect physical and developmental disorders, which parents might overlook, and another one is to offer an opportunity for parents to discuss their worries about the daily care for their children. Each municipality takes initiatives to conduct health examination for infants aged 3~6 months, 1.5 years, and 3 years.

Different professionals have an important role in each. Pediatricians examine stature, growth, nutrition, physical state and intellectual development of children. Public health nurses (PHNs) organize the health examination and discusses the worries of mothers about the daily care of infants. Psychologists sometime attend the health examinations, and consult with mothers whose worrying is more serious. A dental assistant also examines the teeth in toddlers. An alimentation instructor also attends the examination and advises how to make baby food.

The national data in Japan<sup>1)</sup> shows a remarkably good attendance ratio for the health examinations. In 1999 for example the averaged attendance across Japan for 1.5 year-old examination was 90.8 %, ranging from 83.9 to 97.2 %, and in the 3 year-old examination 87.6 %, with a range from 75.8 to 96.7 %. Almost mothers who attended to the health examinations were satisfied with the suggestions or advice from pediatricians and other staff.

Since special attention is given to congenital or perinatal abnormalities at medical institutions, the main disorder discovered at the health examination is related to developmental delay, especially language delay. However, misjudgment or over judgment is included in the first step examination, so the second examination is necessary in order to give advice about development and observe the progress children. The first examinations are held in each municipality and the second examinations, which require advanced examination, are held in prefectural public health centers. After the second examinations, children diagnosed obvious developmental disorders are referred to hospital for medical checks. Finally, almost all children with intellectual deficiencies (ID) are referred to special centers for disabled children for early intervention treatments.

There are several types of special centers for disabled children in Japan. One of the centers has the capacity to care for the children with motor impairments and developmental disorders, while another is for developmentally retarded children only. Some of the special centers also provide intensive medical treatments.

#### Current problems in Japan

There are several problems with these health examinations. Two of them are so serious that they need to be resolved without delay.

### 1) The children with learning disorder, AD/HD and high functioning PDD

The first problem with the health examination in Japan is that there is insufficient examination and consultation for children with mild ID or borderline. Also children with learning disorders (LD), attention deficit/hyperactivity disorders (AD/HD), or high functioning pervasive developmental disorders (HFPDD) are passing through the 3 year-old examination undetected. Their clinical symptoms are not usually diagnosed until just before enrolling in primary school, and sometimes not until after.

Many of them pass the 3 year-old examination, yet their developmental problems can mean they have serious difficulty adapting to school. Some suffer psychosomatic complaints and others quickly show scholastic underachievement. Finally, some of them refuse to go to school. This is a current problem in Japan. The health examination system does not play enough of a role in helping to avoid this predicament.

The cause of this problem is the deficiency of the health examination system. The 3 year-old examination is the last one in Japan. After 3 year-old examination, there is no opportunity for parents to discover and recognize mild developmental problems in their children. Parents frequently misunderstand with children who show hyperactive behavior, uncommunicative manner among kids or dyslexics since they have no obvious problems. These children enroll in mainstream schools without their parents and school teachers knowing that they have developmental disorders. There is no special care in mainstream classes. As the result, many such children with mild developmental problems suffer difficulty in adapting to school<sup>2)</sup>.

To resolve this, an additional health examination directed towards diagnosing those children with borderline intelligence, LD, AD/HD and HFPDD should set up around 5 year-old (Fig. 1). Recently in Tottori prefecture, some municipalities started up 5 year-old health examination since 1996. More than 80 % of children and parents attend the examination. Most common health problem is obesity, and the next is language developmental delay and dysarthria. Some dysarthric children were referred to the developmental center and were treated by a speech therapist. Children with typical AD/HD and dyslexia were also found at the 5 year-old examination. They were cared for adequately and then there was less difficulty in adapting to school.

