

Supports for Families of Children with Developmental Disorders

*Development of Parent Mentor System
and Parent Training in Japan*

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At a workshop hosted by Vietnam Autism Network
2017

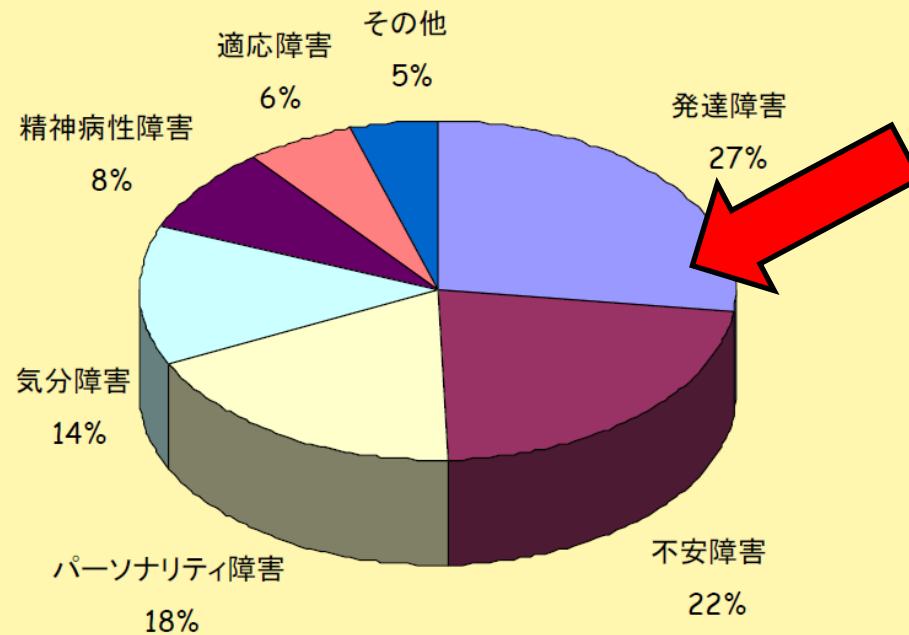
The support law for people with developmental disorders(2005)

- Definition of Developmental Disorders in Japan
 - *Brain dysfunction that is generally expressed during earlier age such as pervasive developmental disorder(autism, etc.,) learning disability, attention deficit hyperactivity disorder, etc*
- Important Points
 - Early Screening and Support
 - Educational Support in School
 - **Family Support**
 - Vocational Support
 - Establishment of Center for Developmental Disabilities at all 47 prefectures and designated cities

Other Issues about Developmental Disabilities in JAPAN

- Abuse
- Domestic violence
- School refusal (non-attendance)
- Social withdrawal
- Addiction of internet and on-line game
- It is indicated that those factors are related to developmental disabilities.

Social Withdrawal (Kondo, 2009)



来談事例125ケースから得たDSM-IV第I、II軸診断の総数170個。上記%は全診断数中での比率。

(近藤直司, 2009)

Prevention

- **Early Screening and Diagnosis System**
- **Early Training System**
- **Early Family Support System**
 - **Peer Counseling of Parent Mentor**
 - **Parent Training**
- **The family support from an early stage is necessary for prevention**

Parent Mentor System

What 's the Parent Mentor?

PM can consult and help for young parents!

子育てにひとりで悩みを抱えていませんか？

就学を控えて、不安。
今まで的人是はどうして
いたんだろう？

診断を受けたけど、
これからどのように
暮らしていったら
いいのだろう？

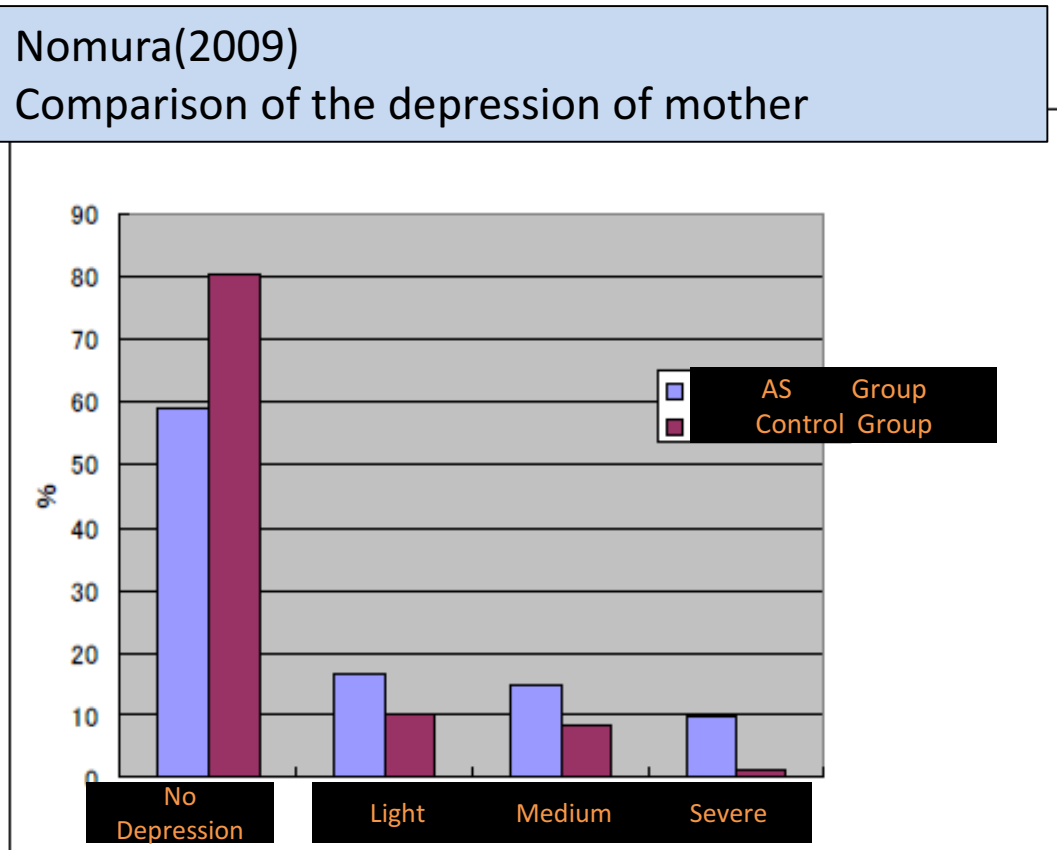
ちょっと
話を聞いて
欲しいなあ。

地域の中で
子どもが気がねなく
遊べる所は？

ペアレントメンターに相談を
してみませんか？

ペアレントメンターとは…よき相談相手。先輩保護者の意です。

10% of mothers having a child with ASD have severe depression



The depression (score of BDI) of mothers having a child with ASD is higher than the control group.

What is the opportunity of the acceptance for mother of the child with ASD?(Ishimoto & Ohi 2008)

Factors	Score of Means
Advice from doctor	2.582
Information from internet or books	2.746
Family support	3.612
<u>Support of peers</u>	3.612
Love of child	3.761
Child raising	3.672

Encounter with the friend of a parent having the child with ASD

Why is PM necessary?

- In Japan, the number of children with developmental disabilities is estimated to be 6.5% (2012).
- Parents having a child with developmental disabilities have many difficulties with child care and have a high risk of depression.
- Parents have difficulties understanding and accepting a child's diagnosis.
- Experienced parents with children who have developmental disabilities can support young parents.

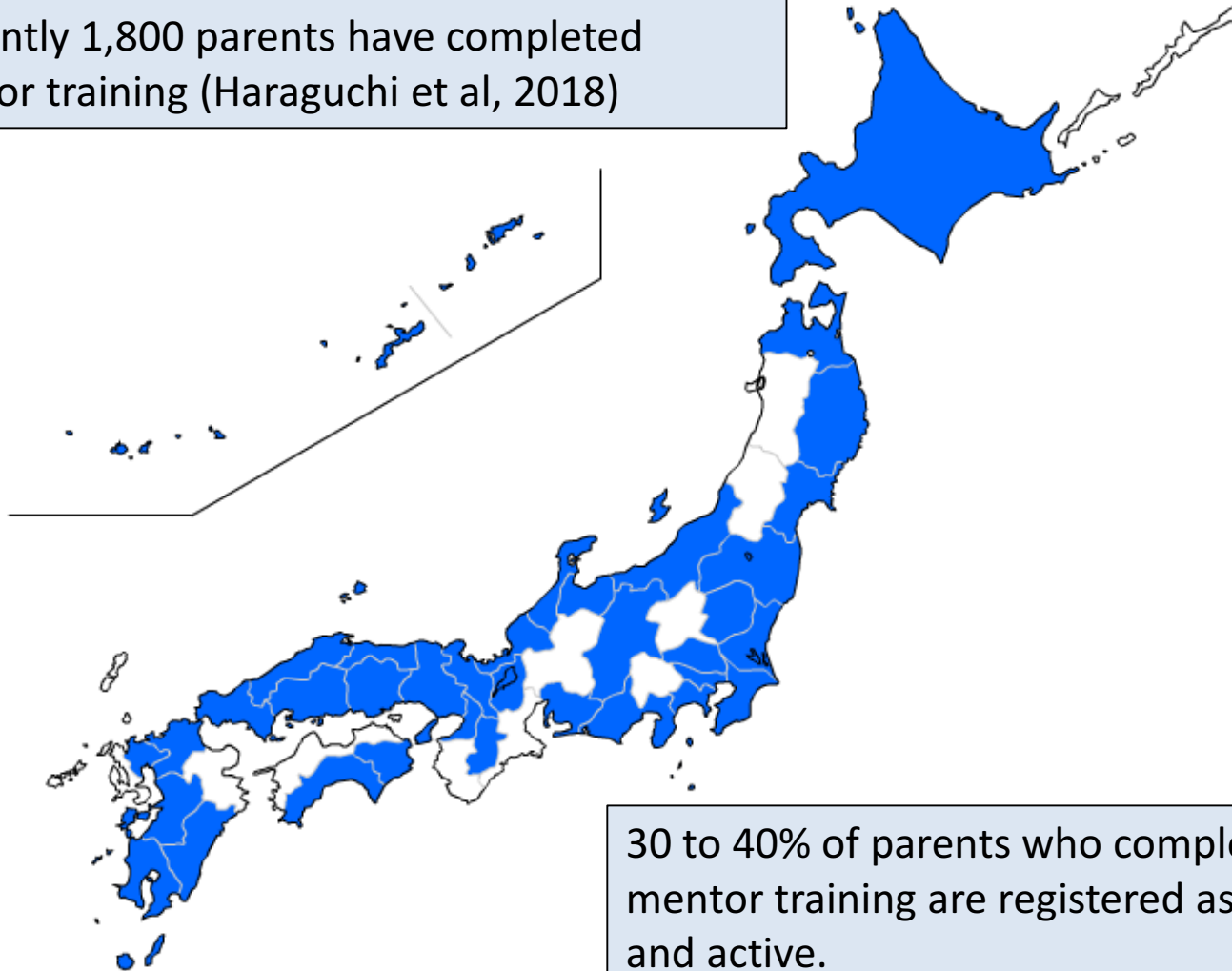
History of PM in JAPAN



- 2005
- We were supported by the nippon-foundation, began the training workshop for the PM.
- 2010
- Ministry of Health, Labour and Welfare established PM support system for developmental disabilities as the important policy

Extended of the PM activity

Currently 1,800 parents have completed mentor training (Haraguchi et al, 2018)



30 to 40% of parents who completed mentor training are registered as mentors and active.

The Role of Parent Mentors

1. Empathize and guide young parents as someone with similar experiences.
2. Provide useful information about the local resources for developmental disabilities.
3. Introduce support agencies.

Characteristics of the Parent Mentor

1. Highly Empathetic
2. Having useful supportive information from an experienced parent's perspective

But these characteristics have several risks

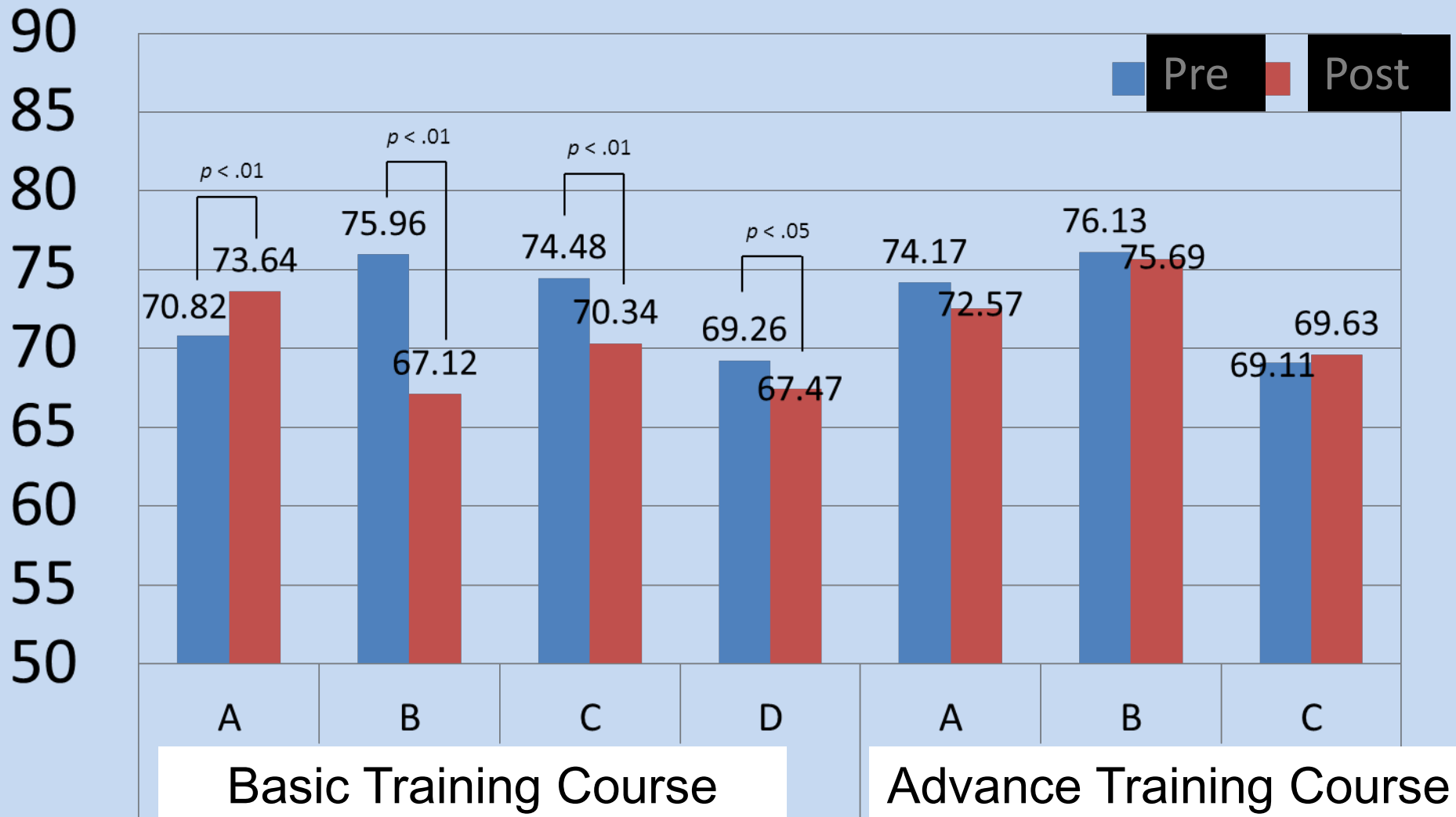
Training Program of PM

- Basic Training Course
 - 2 day Workshop
- Advance Training Course
 - 2 day Workshop
- Follow-up Training Course
 - 1 day per year



The effects of mentor training

Takezawa, Yoshikawa & Inoue 2012



The General Activities of a PM

The family support needs are different
in each prefectures

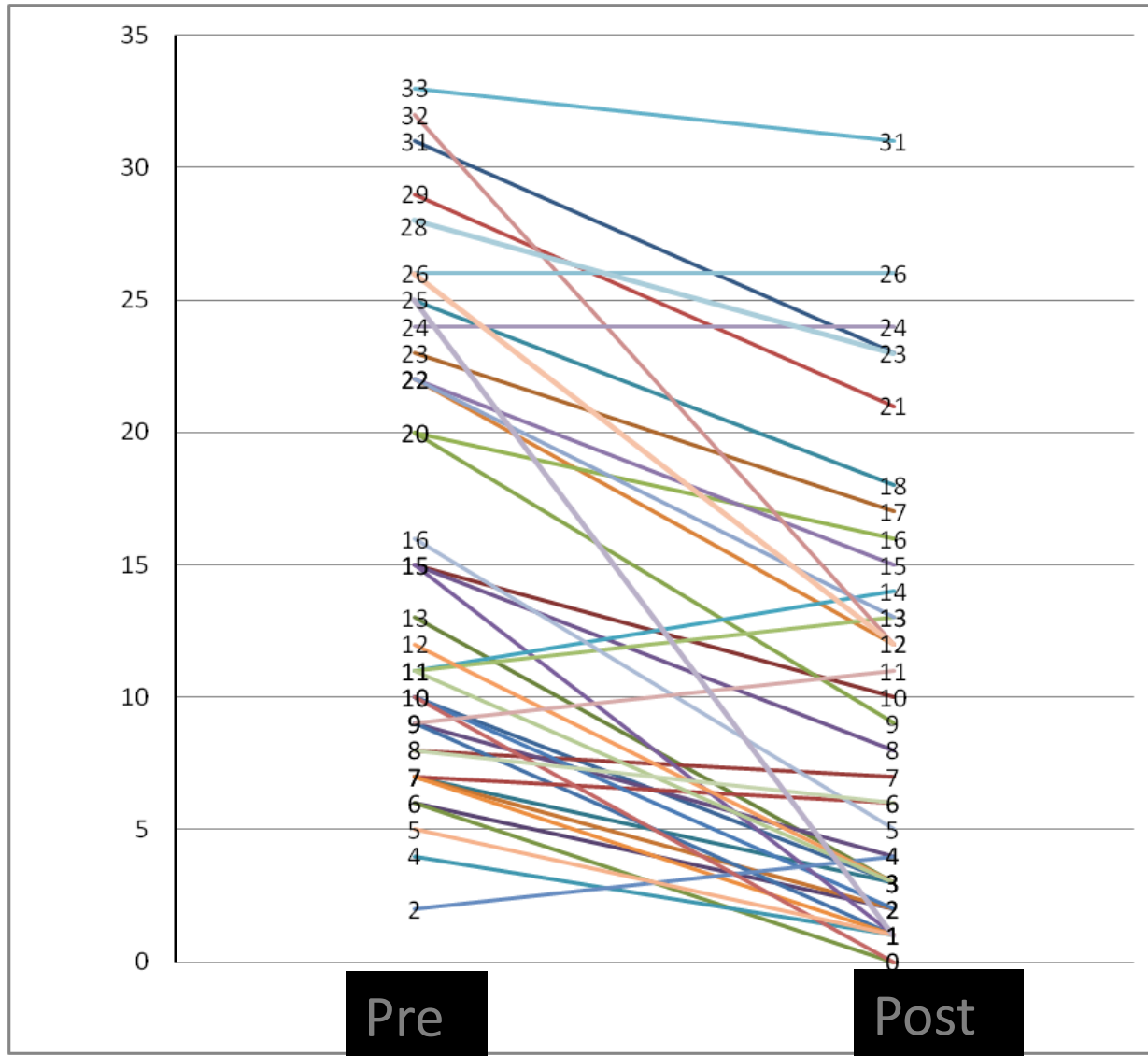
- *Making support book workshop*
- *Peer counseling*
- *Telephone counseling*
- *Enlightening activities about development disabilities*
- *Parent training (sub staff)*

Peer counseling



Before the children enter school, young parents must decide their schools. In this period , parents' stress is the most high. PMs can speak their experiences.

The Effect of Parent Training(Mentor Joined as Staff)



The change in depression scores (n=42)

Cooperation and Activity of PM

Parents

Examples of situations where a parent mentor is necessary

Before diagnosis

Selection of the school for child

Having conflicts for a child care

Support Needs

Medical Center
Counseling Center

Collection

**Steering Committee
& Coordinator**

Peer Support

Parent Mentor

Collection

Training
Matching
Advice



特定非営利活動法人

日本ペアレント・メンター研究会

Japan Society for the Study of Parent Mentor

平成23年設立

特定非営利活動法人

日本ペアレント・メンター研究会

Japan Society for the Study of Parent Mentor

We are providing training programs and consultation about PM activities to local governments and support organizations in Japan.

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Parent Training for Developmental Disabilities

Parent Training for Developmental Disabilities

- Parent training devolved in the United States since the 1960s(Patterson & Gullion,1968)
- Many skills were targeted
 - Problem behavior, Self care skills, Academic skills , Play skills, Communication skills etc
- In Japan as well, parent training programs for children with developmental disabilities, such as the Hizen, Seiken, Nara, and Tottori University styles, have been developed since the 1990s.
- For the past few years, parent training has been conducted in various places such as local governments, medical institutions, and developmental support organizations in connection with the Ministry of Health, Labor and Welfare's "Developmental Disability Support System Development Project".

Parent Training for Developmental Disabilities

- It is carried out by 335/1741 local governments nationwide(JDDnet, 2019).
- Program contents
 - Group of 5 to 8 people
 - 5-8 consecutive courses
 - Learn how to interact with children with developmental disabilities through lectures, role play, and homework.

Effect of Parent Training for Developmental Disabilities

- Children
 - Reduction of problem behavior
 - Acquiring adaptive behavior and communication skills
- Parents
 - Reduction of stress and depression

Effectiveness of behavioral group parent training (GPT) for parents of children with ASD Inoue & Haraguchi (2011)

Training components

1. Lecture on behavior modification
2. Group activity and discussion
3. Home work

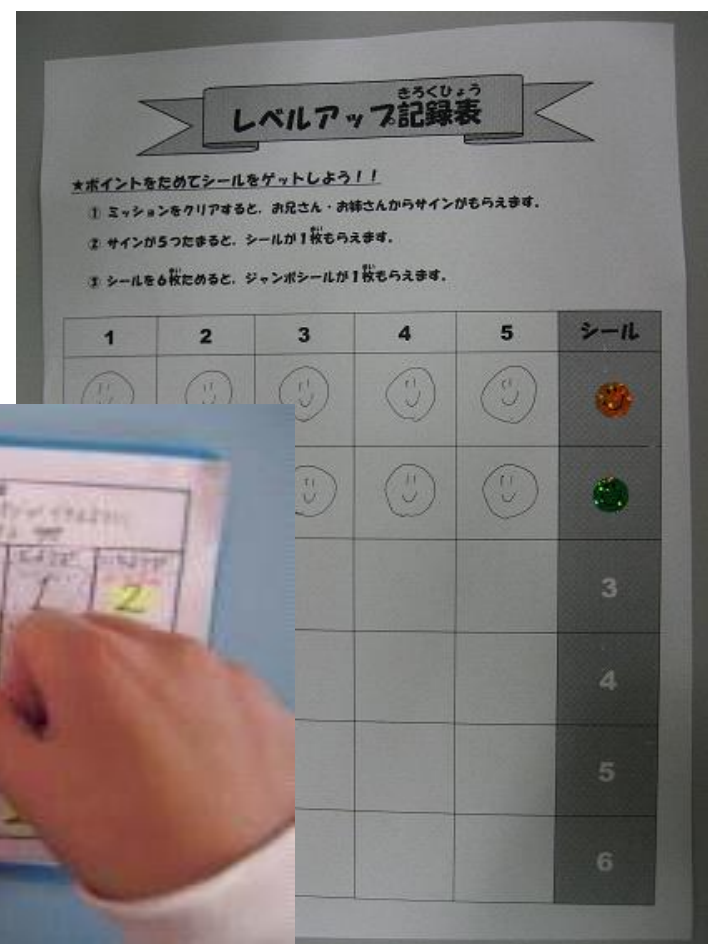
One Session → 2 hours

Total 9 sessions



Method of Reinforcement

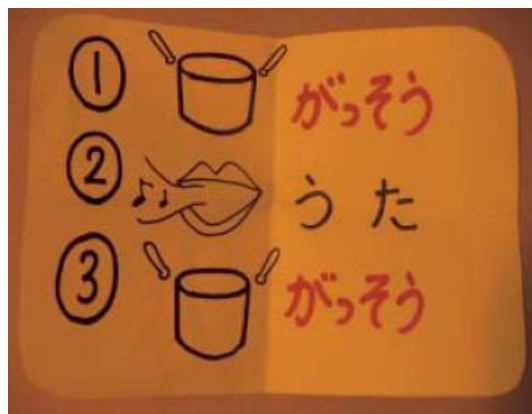
Introduction of Token System



Method of Control of Antecedents

Scheduling

いえ
 ↓
 くるま
 ↓
 ヨーカどう
 ↓
 しゃくひんうりば
 ↓
 おもちやうりば
 ↓
 くるま
 ↓
 いえ



12月のよてい

げつようび	かようび	すいようび	もくようび	きんようび	どようび	にちようび
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

Group Activity & Discussion

• #2 “How to Praise”

This group activity aims to promote parents' praising of the child.

The sheet on the right shows two scenes with mother calling out “Dinner's ready.” in each.

Scene 1: The boy replies, “OK.” and comes without putting away his toys.

Scene 2: The boy doesn't reply but begins putting away his toys.

The parents are asked to notice the good behavior in each and practice giving positive words.



たろう君が、部屋いっぱいにおもちゃを広げて遊んでいます。
お母さんが「ごはんよ」と声をかけました。
いつもはおもちゃの片づけどころか、呼んでもなかなか遊びをやめられません。

でも今日は少し違うようですね。
あなたならどんな言葉でほめますか？



フキダシの中に、ほめ言葉を書いてください。



Blank space for writing a positive word.



フキダシの中に、ほめ言葉を書いてください。



Blank space for writing a positive word.

Group Activity & Discussion

The “Home Work Program” targets specific parenting needs and is created with the advice of staff.

	7/5 日	7/6 月	7/7 火	7/8 水	7/9 木
1. えんぴつをけずる	○	△	△	△	△
2. じかんわりをじゅんぴする。	◎	◎	◎	◎	△
3. ひきざん する。	○	◎	◎	◎	△
4. たしざん する。	◎	◎	◎	◎	△
5. れんらくちょうを見て、持ってくるものを入れる。	—	△	◎	◎	△
6. れんらくちょう・しゅくだい <small>提出物</small> を入れる。	△	◎	◎	◎	△
7. ふでばこを入れる。	◎	◎	◎	◎	△
8. 給食セットを入れる。	△	△	△	◎	△

てつづき作成表 [6月9日 ~ 7月9日] 名前

■課題名 (具体的に) 次の日の学校の準備をする

開始 →

1 誰が(かかわる人) 母親 又は 父親	2 いつ 宿題の後 → 全針 ・夕食前 終わる 寝る前	3 どこで(教える場所) 子供の机
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4 環境の工夫 チェックシート	5 言葉かけ・指示するもの 「明日の準備するよ」	6 準備するもの 時刻
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7 目標とする子どもの行動	8 困難な場合の援助
① 小てはこに入. 7. いえんぴつをすずる	
② 時刻表を見る	
③ 子供のよい教科書の道具を抜く(かぎ)	
④ 子供の机 " に入れる(かぎ)	
⑤ 連絡帳を見. 持. 7. くるものを入れる	
⑥ 宿題(ポイント等)を入れる	→ 連絡帳・宿題・提出物 とうと 感じ
⑦ 小てはこを入れる	ひととめに 7. 入れ. 7. 提出しやす.
⑧ 給食セットを入れる	よくに 17. 7. どうか?
⑨	
⑩	

9 できたときのほめ方やかわり方
頭をなてる → 抱きしめる

10 達成基準

① ~ ④

YES →

達成! 次の目標へ

NO →

①に戻って見直し

	MR	Non-MR
	Group A	Group B
	Participants N=66 (M 7, F 59) age range, 28-53 years mean age, 37.4 years	Participants N=38 (M 4, F 34) age range, 32-49 years mean age, 38 years
PDD	Children N=65 (M 58, F 7) age range, 25-199 months mean age, 82.7 months	Children N=39 (M 37, F 2) age range, 47-172 months mean age, 95.6 months
	Group C	Group D
	Participants N=18 (M 1, F 17) age range, 28-47 years mean age, 38.5 years	Participants N=9 (F 9) age range, 35-54 years mean age, 40.6 years
Non-PDD	Children N=17 (M 12, F 5) age range, 6-204 months mean age, 86.4 months	Children N=9 (M 9) age range, 93-167 months mean age, 113.6 months
*Others	Participants N=10 (M 5, F 5); age range, 31-52 years; mean age, 40 years Children N=8 (M 7, F 1); age range, 3-177 months; mean age, 73.6 months	

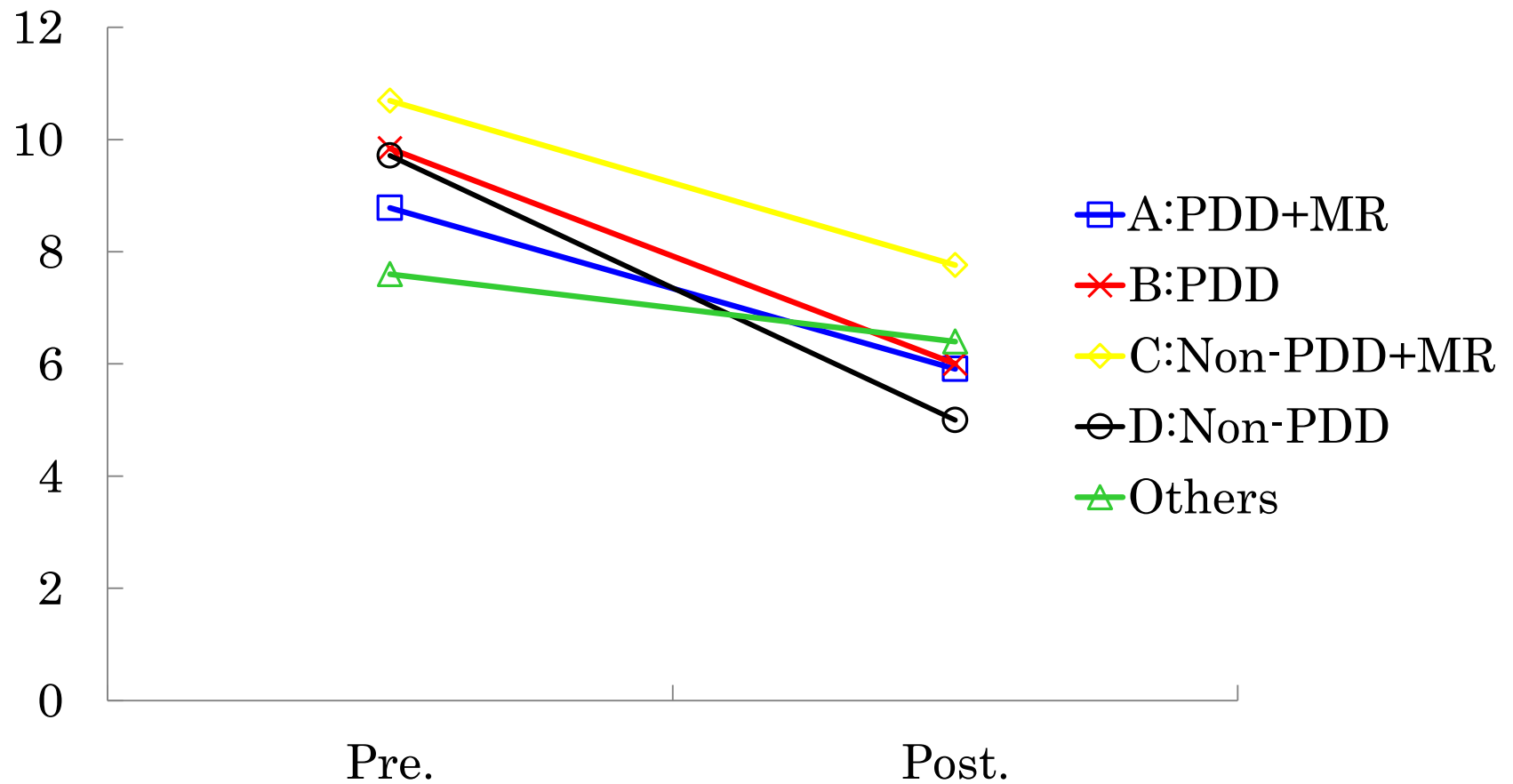
Tasks and Achievement Among the Groups

Skills	Group A (N=61)			Group B (N=35)			Group C (N=16)			Group D (N=9)			Others (N=4)		
	Tasks (N)	Achievement (N)	Ratio (%)	Tasks (N)	Achievement (N)	Ratio (%)	Tasks (N)	Achievement (N)	Ratio (%)	Tasks (N)	Achievement (N)	Ratio (%)	Tasks (N)	Achievement (N)	Ratio (%)
Self-care	83	32	38.6	33	18	54.5	20	10	50.0	7	1	14.3	5	3	60.0
Domestic	68	32	47.1	32	24	75.0	8	5	62.5	6	5	83.3	0	0	—
Academic	9	4	44.4	25	17	68.0	6	6	100	9	7	77.8	1	1	100
Play	5	1	20.0	2	1	50.0	0	0	—	1	1	100	1	0	0
Communication	10	6	60.0	1	0	0	2	0	0	0	0	—	0	0	—
Others	4	3	75.0	3	2	66.7	0	0	—	1	1	100	0	0	—
Total	179	78	43.6	96	62	64.6	36	21	58.3	24	15	62.5	7	4	57.1

For groups A and C, comprising children with mental retardation, parental request for self-care tasks was high. Achievement rate for these two groups was relatively low due the program's time frame.

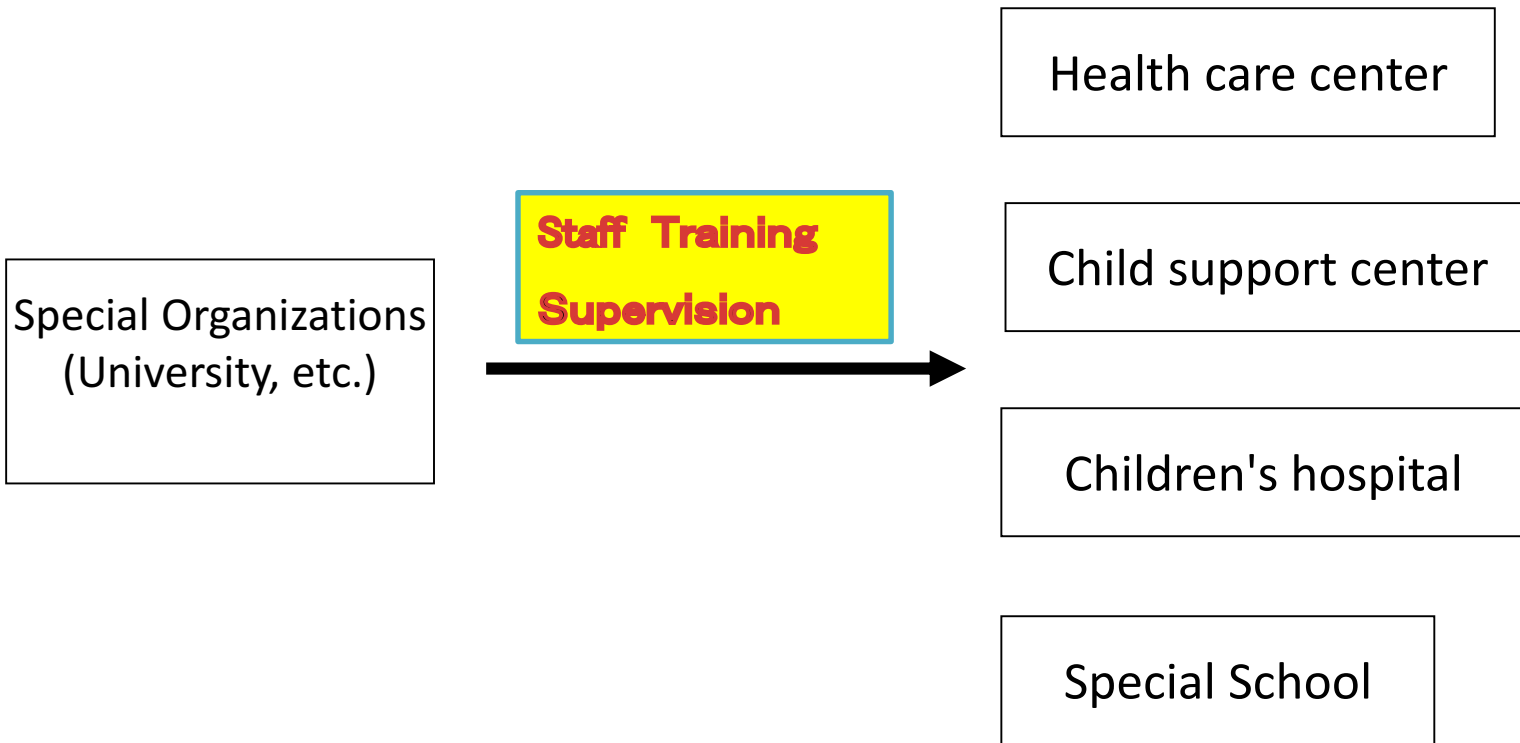
General Health Questionnaire (GHQ30 Japanese version)

Mean of GHQ score



Future Direction of PT in Japan

We hope to extend the reach of the PT program by making it available through a larger number of public entities.



I hope that PM & PT develops as an effective family support system in ASEAN.

THANK YOU