Chapter #20

THE EFFECTIVENESS OF A MUTUAL EXCHANGE SUPPORT PROGRAM FOR PARENTS OF CHILDREN WITH DEVELOPMENT DISORDERS

Yutaro Hirata[1], Yutaka Haramaki[2], & Yasuyo Takano[3]
[1]Kagoshima University, Japan
[2]Hiroshima University, Japan
[3]Aichi Shukutoku University, Japan

ABSTRACT
There is an urgent need to support families of children with developmental disorders, especially when such families must help each other. However, practice and research related to support systems for families have only recently begun in Japan. Considering these issues, the authors developed a program to support mutual exchanges among parents of children with developmental disorders. This study aimed to verify the effectiveness of the program and examine the relationship between participants' program experience and its effectiveness. The participants included 21 male and female parents of children with developmental disorders. Effectiveness indicators included the Profile of Mood States 2nd Edition-Adult Short (POMS2-A) (before and after implementation), Session Impact Scale (SIS), and Interaction Experience Rating Scale (IERS). This study indicated that our program had the effect of reducing negative feelings for parents of children with developmental disorders through a comparison of pre-and post-program data, as well as the correlation between IERS item responses and the amount of change in mood states, particularly reflecting on their own children. Additionally, the relationship between the participants' evaluation of the program and the change in their POMS2-A scores following the intervention should be examined with a larger sample.

Keywords: developmental disorder, family support, interaction support, program development, profile of mood states 2nd edition.

1. INTRODUCTION

Parents who are raising children with developmental disorders, face challenges in terms of mental health (Hayes & Watson, 2013) and family functions (Jellet, Wood, Giallo, & Seymour, 2015). Their difficulties are invisible and cannot be shared with other people (Jellet et al., 2015). Solomon, Pistra, and Barker (2001) reported that parents of children with developmental disorders and special needs had feelings of grief, loss, and guilt; they commonly experienced psychological, social, financial worries, stress, ill health, and political consequences such as isolation and social marginalization, stigmatization, and disempowerment. Specifically, common challenges include "I don't know how to treat my child," "My family gets tired of being overwhelmed by my child's behavior," "I am worried about the future," "People around us don't understand my child or our feelings," and "I am worried about my siblings."

Jellett et al. (2015) investigated the relationship between child behavior problems and family functioning in families where a preschooler has an autism spectrum disorder (ASD). The study indicated that behavioral problems in children with ASD were associated with

depressive symptoms, such as stress and fatigue, in parents and less effective family functioning. Parents' depressive symptoms such as low mood and lack of enthusiasm and initiative can make it harder for them to function, which can then impact family life.

Solomon et al. (2001) investigated the benefits of mutual support groups for parents of children with disabilities. The study showed that parents of children with disabilities and special needs who belonged to a support group experienced changes in three broad areas: sociopolitical, interpersonal, and intraindividual, leading to a change in identity for parents. First, parents in the groups experienced changes in the outside world (in the sociopolitical domain), gaining a sense of control and agency. These changes were partly derived from the "experiential knowledge" shared by people who had experienced similar situations. Second, parents experienced changes in the interpersonal domain, such as belonging to a community, being understood, and accepted, as well as having friendships and social networks where they could share emotions and feel more "normal." Third, parents experienced changes in the intraindividual domain, such as feelings of increased self-esteem and confidence, less guilt and self-blame, and greater acceptance of their child's disorders. This study suggested that the groups seemed to enable these parents to define themselves more positively and to ascribe more positive meanings to having a disabled child. Additionally, in the study, parents who rated their group as highly focused on self-discovery were more satisfied and found the groups more helpful, suggesting that the opportunity to explore and develop one's own sense of self was a key component of a positive group experience.

In Japan, the law for supporting people with developmental disorders was amended in 2008 and revised in 2016. There are three main aims of the law: first, to define developmental disorders and promote their understanding; second, to promote support for people with developmental disorders; and finally, to achieve close cooperation among mutual sections responsible for supporting people with developmental disorders (Ministry of Health, Labour and Welfare, 2016). According to this law, it is very important to include families to promote support systems for people with developmental disorders.

There is an urgent need to establish a system to facilitate mutual support among people with developmental disorders and their families. The importance of support and connection among parents has been demonstrated by numerous practices and initiatives in Japan and abroad, such as the Parent Mentor Program (Haraguchi, Ogura, Yamaguchi, & Inoue, 2020; Inoue, 2008; Santelli, Turnbull, Marquis, & Lerner, 1995). Such activities are not limited to developmental disorders. They have been implemented in several initiatives in Japan and abroad. Parents can alleviate their loneliness during child rearing by participating in such activities. Further, they can gain a sense of security (Ainbinder et al., 1998), and feel empowered (Law, King, Stewart, & King, 2002) through their participation. Besides positive psychological changes, such as information acquisition (Inoue, 2008) and improvement of skills (Law et al., 2002), parents can gain valuable skills and knowledge with regard to parenting. These previous studies suggest that parents who share similar experiences can benefit from mutual interactions in various ways.

Against this background, the Ministry of Health, Labor, and Welfare (2019) proposed the creation and expansion of a new set of family support services. However, even the Parent Mentor program—currently the most systematic program of its kind in Japan—has commenced only recently. The need for further discussion on effective activities and support systems is thus evident (Haraguchi, Kato, & Inoue, 2015).

Porter and Loveland (2018) reviewed 15 primary research articles (2000–2015) on parenting stress in mothers of Japanese children with autism to identify the factors that influence parenting stress in such mothers. They indicated that Japanese mothers demonstrated stress related to attachment difficulties, low parenting efficacy, and lack of

support, reflecting Japanese parenting styles and gender ideology. They suggested that parent-directed and culturally calibrated interventions are needed to support parents of children with autism, especially parents who belong to a cultural minority.

Previous studies have emphasized the need for various child-centered services, while highlighting their utility for the mental health of parents (especially, depressive states and low mood) to maintain effective family functioning.

2. OBJECTIVES

The authors have been working with the Developmental Disabilities Support Center of Saga Prefecture (hereinafter referred to as YUI) for over 10 years to train mentors for parents of children with developmental disorders. Based on this experience, we developed a parental support program for parents of children with developmental disabilities that allowed them to experience mutual support in a safe and professionally structured setting. Based on the awareness of previous research and our empirical problem, we developed a program to support mutual interactions among these parents.

The purpose of this study was to determine whether our program had an effect on the mood states of parents of children with developmental disorders, and whether changes in mood states were related to parents' experience of the program.

3. METHODS

3.1. Target group

The program that we developed for parents of children with developmental disorders was announced through program flyers and YUI's website in the Saga area. Twenty-one male and female parents of children with developmental disorders voluntarily participated in the study. Their ages ranged from 30s to 50s (4 in their 30s, 14 in their 40s, and 3 in their 50s). The demographics of the children were as follows: three preschoolers, three in the first or second year of elementary school, five in the third or fourth year of elementary school, one in the upper grades of elementary school, two in junior high school, and seven in high school or older (including siblings). The children's diagnoses were as follows: autism spectrum disorder (ASD), 13 (including one suspected case); ASD + attention deficit hyperactivity disorder (ADHD) + learning disorders (LD), 3; ASD + intellectual disorders (ID), 1; developmental disorders (DD) + ADHD + developmental coordination disorder (DC), 1; none, 1; not reported, 2.

Table 1.
Participant demographics.

Demographics	n = 21	
	n	%
Children's stage		
Preschoolers	3	14.3
First or second year of elementary school	3	14.3
Third or fourth year of elementary school	5	23.8
Upper grades of elementary school	1	4.8
Junior high school	2	9.5
High school	7	33.3
Children's diagnoses		
ASD	13	61.9
ASD+ADHD+LD	3	14.3
ASD+ID	1	4.8
DD+ADHD+DC	1	4.8
None	1	4.8
Not reported	2	9.5
Parent's Age		
30s	4	19.0
40s	14	66.7
50s	3	14.3

Note. Including sibling. ASD = autism spectrum disorder ;
ADHD = attention deficit hyperactivity disorder ; LD =
learning disorders ; ID = intellectual disorders ; DD =
developmental disorders ; DC = developmental coordination
disorder

3.2. Procedures

In this study, we examined the program's effectiveness through parents' mood, session helpfulness, and interaction experience. This study investigated the relationship between the program experience's evaluation and its effects and clarified the program's mechanism.

The procedures were programmed to (0) answer for index (pre-POMS2), (1) Mini-lecture on common experiences (e.g., the various experiences and stresses of parents with children with developmental disorders), (2) Reflection on the good aspects and efforts of children and parents (e.g., individuals will be asked to reflect on their daily activities by writing them down on a worksheet), (3) listening training (e.g., explanation of the key points of listening and practice), (4) group work using psycho-educational methods (e.g., share the content of the reflection with the group of parents), (5) question-and-answer session and free talk time (e.g., communicate with staff about the program itself and any questions that arise during sharing), (6) answering for indices (post-POMS2, IER, and SIS), and (7) free talk time

(e.g., parents who want to talk are free to talk to other parents and staff). We planned the program in a manner that enabled the participants to have mutual interactions throughout.

The sessions were 2 hours long, with mini-lectures lasting about 30 minutes and group work lasting about 1 hour and 10 minutes. In addition, there was one session each.

The program was implemented by one main staff member and three to four support staff members. Support staff members joined the groups and acted as facilitators. All staff members were licensed psychologists.

3.3. Effect indices and data analysis

The POMS2-A, which has been used to explore the effectiveness of a wide range of clinical interventions, was implemented at pre-and post-program sessions to evaluate changes in participants' mood states.

Following Solomon et al. (2001), session helpfulness was measured using a single-item measure employed by Elliot and Wexler's Session Impact Scale (SIS) (Elliot & Wexler, 1994) that asked, "Please rate how helpful or unhelpful to you the group is, overall." The response scale ranged from 1 (extremely unhelpful) to 9 (extremely helpful) with a neutral midpoint (neither helpful nor unhelpful). This measure is highly correlated with other, more complex, indices of helpfulness (Stiles et al., 1994).

We originally developed the interaction experience rating scale (IERS) (17 items) to assess participants' experiences regarding mutual support. This scale was based on participants' self-reports in the previous trial sessions. Participants responded to each item on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree).

SIS and IERC scales were implemented after the program.

IBM SPSS Statistics 27 software was used to analyze the data. A *t*-test was performed to examine the POMS2-A pre-and post-program implementation, and Spearman's rank correlation analysis was conducted to identify the relationship between participants' evaluation of the interaction support program and its effect on mood states. We compared their pre-and post-program scores on the POMS2-A with their scores on the IERS items.

4. RESULT

4.1. Effectiveness of the implementation of the program
4.1.1. Effects of the program for parents' helpfulness

Participants' helpfulness in the single-item SIS average score was 8.0 (n=21, minimum=5, maximum=9, SD=1.00), which is considered very high.

4.1.2. Effects of the program for parents' mood states

The effects of the program implementation are shown in Table 1. The Time 1 (pre-program) POMS2 scores on AH, CB, DD, FI, and TA were significantly higher than the Time 2 (post-program) scores. No significant differences were observed in the F, VA, and total mood disturbance (TMD) scores (Table 2).

Table 2.
Comparison on the POMS2-A before and after the program.

Variable	Time 1		Time 2		t(21)	p	95% Cl		Cohen's d
	M	SD	M	SD			LL	UL	
AH	49.00	9.31	40.90	4.55	4.77	<.001	4.56	11.63	1.04
CB	53.90	9.68	46.38	7.21	4.31	<.001	3.88	11.16	0.94
DD	51.24	9.16	46.62	7.23	2.88	.009	1.28	7.96	0.63
FI	48.76	14.30	38.67	5.94	3.63	.002	4.29	15.90	0.79
TA	52.76	12.13	44.62	8.47	3.61	.002	3.43	12.85	0.79
VA	52.57	8.66	55.05	10.23	-1.75	.095	-5.42	0.47	-0.38
F	55.00	8.25	57.71	12.12	-1.72	.100	-6.00	0.57	-0.38
TMD	50.58	11.10	47.09	7.07	1.72	.101	-7.39	7.69	0.38

Note. Cl = confidence interval; LL lower limit; UL upper limit; AH = Anger-Hostility; CB = Confusion-Bewilderment; DD = Depression-Dejection; FI = Fatigue-Inertia; TA = Tension-Anxiety; VA = Vigor-Activity; F = Friendliness; TMD = Total Mood Disturbance.

4.1.3. Effects of the program on parents' experiences

The authors created items of the IERS using free descriptions of the program obtained before the survey was conducted. Cronbach's alpha was used to test the questionnaire's reliability, yielding a coefficient of 0.87, and Guttman's folded half method reliability yielded a coefficient of 0.73—close to 1. Table 3 shows that IERS scores, which, except for the v4 item, were very high.

Table 3.
The means of interaction experience rating scale (IERS).

Number	Questions	means	SD
v1	I learned a lot about communication	4.05	0.74
v2	I was able to gain new perspectives and ideas through interaction with other parents	4.43	0.51
v3	I have gained new knowledge	4.33	0.58
v4	I got the information I needed to know	3.86	0.85
v5	It gave me an opportunity to reflect on my child	4.67	0.48
v6	It gave me an opportunity to reflect on myself	4.43	0.93
v7	I was able to notice the good things about my child	4.43	0.68
v8	I was able to notice my child's efforts	4.57	0.60
v9	I could notice my own efforts	4.43	0.68
v10	It gave me an opportunity to interact with other parents	4.76	0.44
v11	I felt safe talking to other parents	4.62	0.50
v12	I felt more comfortable through interaction with other parents	4.43	0.51
v13	Interacting with other parents helped me to feel that I am not alone	4.62	0.50
v14	I was able to have a good time through interaction with other parents	4.52	0.51
v15	I will try to attend the next course when it is held	4.52	0.75
v16	I would like to have more opportunities to interact with other parents in the future	4.62	0.50
v17	Increased motivation to raise children in the future	4.38	0.59

IERS: Interaction Experience Rating Scale

4.2. Relationship between program evaluation and the amount of change in POMS2-A

Spearman's rank correlation analysis was used to investigate the effectiveness of the program content (Table 4). The results showed that single-item SIS scores were not associated with any changes in the state of a participant's mood. One of the IERS items, "It gave me an opportunity to reflect on my child," was positively correlated with a reduction in scores on CB (r(21)=.589, p< 0.01), DD (r(21)=.436, p< 0.05), FI (r(21)=.435, p< 0.05), TA (r(21)=.530, p< 0.05) and TMD (r(21)=.611, p< 0.01). Similarly, the item, "It gave me an opportunity to reflect on myself," had a positive correlation with a reduction in scores on CB (r(21)=.598, p< 0.01). Furthermore, the items "It gave me an opportunity to interact with other parents" and "I would like to have more opportunities to interact with other parents in the future," had a positive correlation with an increase in scores on F (r(21)=.471, p< 0.05, and r(21)=.728, p< 0.01, respectively).

A total of 136 correlation analyses were performed. After controlling for FDR, the eight correlations that had previously been significant association were reduced to one significant association (bolded in Table 4).

Table 4.
Correlation between item responses and changes in the participants' moods states.

Scale / Number	Questions	Amount of change in mood state before and after the program (Post-Pre)							
		AH	CB	DD	FI	TA	VA	F	TMD
SIS	How useful or unhelpful was this course for you?								
IERS									
v1	I learned a lot about communication								
v2	I was able to gain new perspectives and ideas through interaction with other parents								
v3	I have gained new knowledge								
v4	I got the information I needed to know								
v5	It gave me an opportunity to reflect on my child		.589**	.436*	.435*	.530*			.611**
v6	It gave me an opportunity to reflect on myself		.598**						
v7	I was able to notice the good things about my child								
v8	I was able to notice my child's efforts								
v9	I could notice my own efforts								
v10	It gave me an opportunity to interact with other parents							.471*	
v11	I felt safe talking to other parents								
v12	I felt more comfortable through interaction with other parents								
v13	Interacting with other parents helped me to feel that I am not alone								
v14	I was able to have a good time through interaction with other parents								
v15	I will try to attend the next course when it is held								
v16	I would like to have more opportunities to interact with other parents in the future							**.728****	
v17	Increased motivation to raise children in the future								

Note. SIS = Session Impact Scale ; IERS = Interaction Experience Rating Scale. Bolded measures indicate measeure that remained significant after Falese Discoverry Rate (FDR) correection.

5. DISCUSSION

5.1. Effectiveness of the implementation of the program
5.1.1. Effects of the program for parents' helpfulness

The participants of the program felt that their group was very helpful; the helpfulness and satisfaction ratings were strongly correlated, as well as the self-discovery rating (r =.43, p <.001) (Solomon et al., 2001). Helpfulness can be considered an important indicator of whether a program functions effectively when viewed from multiple perspectives.

5.1.2. Effects of the program for parents' mood states

Solomon et al. (2001) reported that parents universally felt that they benefited from the opportunity to share their experiences that groups provided, by finding out other people had experienced, and were experiencing, a similar range of problems and difficulties related to having a child with disabilities.

Informal social support from friends and family reduces stress among mothers of children with ASD (Prata, Lawson, & Coelho, 2019). With regard to positive maternal outcomes, social support received from friends was associated with increased life satisfaction, positive affect, and psychological well-being, whereas partner support was associated with increased life satisfaction and psychological well-being (Ekas, Lickenbrock, & Whitan, 2010).

One of the initial goals of this study was to investigate whether our program improved parents' mental states. Our program provided mutual interaction and networking activity to parents who participated in the mini-lecture, reflection on the good aspects and efforts of children and parents, listening training, group work using psycho-educational methods, and free talk time. In the present study, negative mood states were significantly reduced after the program. It may increase parents' capacity to accept and understand their children's developmental traits and behavioral problems by sharing their experiences during group sessions. Conversely, it did not affect positive feelings (F and VA) or TMD. Japanese mothers of children with ASD may experience additional stress, because they cannot control their children's behavior or their relationship with them, even if their maternal sensitivity is high (Porter & Loveland, 2018). A previous study reported that family support operated indirectly by helping mothers become optimistic, as they confronted the challenges associated with raising a child with ASD by examining the relationship among social support, optimism, and well-being in a population experiencing high levels of distress and mothers of children with ASD (Ekas et al., 2010). The study by Ekas et al. (2010) followed the parents for how long. The current study was conducted in one session. Further, we addressed the common sense and knowledge of parents of children with developmental disorders in the mini-lecture, reflected on the good aspects and efforts of children and parents, listening training, and group work using psycho-educational methods. Participants felt safe and confident about their individual negative feelings because of the program. Therefore, it does not seem to change positive feelings or TMDs. If possible, our program could foster parents' optimism and positive mood states via long-term support. This should be investigated in future studies.

5.1.3. Effects of the program on parents' experiences

Before this study, we conducted several sessions for parents of children with developmental disorders, and the IERS was created from the self-descriptions for the evaluation of the group interaction experiences that the participants of the trial had. The IERS

allows us to learn about the participants' experience of gaining knowledge and skills related to developmental disorders, the reflection on and awareness of their new emotions, feeling safe because of mutual interaction with other parents, and the social support network. The high score of the IERS shows that participants can soften the negative impact of having children with developmental disorders (Bishop, Richler, Cain, & Lord, 2007).

Catalano, Holloway, and Mpofu (2018) suggested that practitioners' guidelines to support the mental health and well-being of parent care should include addressing the parent's self-perspective-taking and skill for real-time problem-solving, through their critical interpretive synthesis systematic review. Our lecture focused on parents' common sense and knowledge; the children's developmental disorder traits included ASD, ADHD, and learning disorder. We took an opportunity to reflect on the good aspects and efforts of children and parents, provide listening training, and group work using psycho-educational methods. The participants indicated high scores regarding reflections for themselves and their children (v5 and v6 of the IERS). Participants might have noticed their new self-perspective-taking skills gained through the program.

Regarding v4, "I got the information I needed to know," the average score was 3.86, the lowest score. It seemed that the program provided wide and common information that participants only partially needed.

The current sample showed a high prevalence of ASD (16/21 children, 76.2%). This high rate may have affected the results because of the limited content and time in the program, specifically targeting ASD. The program did not affect the positive mood states of the POMS2, even though item v17 showed a high score. Past research suggests that optimism and social support are associated with increased well-being among mothers of children with ASD (Bishop et al. 2007). Optimism was negatively associated with each of the negative maternal outcomes and positively associated with each positive maternal outcome. Higher levels of optimism are associated with increased positive outcomes and decreased negative outcomes (Ekas et al., 2010). Therefore, we speculated that participants could feel positive toward raising children; future studies need to examine this speculation to understand the value of maternal sense (IERS) in positive mood states. It was unclear whether this intervention could influence mothers' maternal sense or mood, but parents' mental health includes both of these factors. Therefore, further research is required.

5.2. Relationship between program evaluation and the amount of change in POMS2-A

Social support is a critical factor in reducing the negative psychological impact of raising children with developmental disorders (Ekas et al., 2010; Jellett et al., 2015). Solomon et al. (2001) showed that the parents of children with developmental disorders or special needs in the mutual support groups experienced changes in gaining a sense of control and agency in the sociopolitical domain. These changes were derived, in part, from the "experiential knowledge" shared by people who had experienced similar issues. Parents experienced changes such as belonging to a community, being understood and accepted, and having friendships and social networks where they could share their emotions and feel more "normal" in the interpersonal domain. Finally, parents experienced changes in their feelings, such as increased self-esteem, less guilt and self-blame, and greater acceptance of their child's disorders in the intraindividual domain. In one study, parents who rated their group as highly focused on self-discovery were more satisfied and found the groups to be more helpful, suggesting that the opportunity to explore and develop one's sense of self was a key

component of a positive group experience. They needed to have the opportunity to interact with other parents with similar experiences.

In the present study, we provided mutual interaction opportunities for parents of children with developmental disorders through the program. Interestingly, the program reported that having the opportunity to reflect on themselves and their children was associated with confusion, depression, fatigue, anxiety, and TMD among parents.

The participants in this study had to define themselves more positively and ascribe more positive meanings to having a disabled child, even though the group session took place only once. Moreover, parents may increase their capacity to manage their children's behavior and the impact it can have on the overall family system.

6. CONCLUSIONS

The program that we developed for the parents of children with developmental disorders was effective and helpful.

This paper indicates that our program is effective in reducing negative feelings in parents of children with developmental disorders by comparing pre-and post-program data. The program also found that parents' reflection of their children and themselves was associated with a reduction in negative emotions. Their belief was that having an opportunity to meet other parents who have similar experiences increases their positive feelings.

The opportunity to interact with other parents with similar experiences in a safe and structured learning environment, and the experience of reflecting on their children together, may have helped alleviate feelings of loneliness and provided a sense of security (Ainbinder et al., 1998), even for parents meeting each other for the first time.

This paper confirms the short-term effects of the program. The program provides an opportunity for parents to get what they need. We can indicate that the program contributed to parents' mental health and maternal sense, and the experience of mutual interaction with other parents was viewed as social support.

The total single-session effectiveness of the program was examined in this study; therefore, it was unclear what factors or integrated total factors induced the present results. In the future, it is necessary to further evaluate each factor and the long-term effects of the program.

Additionally, the relationship between the participants' evaluation of the program and the change in their POMS2-A scores following the intervention should be examined with a larger sample.

This was a local area sample, which could limit the generalizability of these findings. Although the participants came from different local areas and met each other for the first time, the mutual interaction was highly favorable and contributed to their mental health. Porter and Loveland (2018) suggested that Japanese mothers also demonstrate stress related to attachment difficulties, low parenting efficacy, and lack of support, reflecting inadequacies in Japanese parenting styles and gender ideology.

Future implementation should consider parenting style, gender ideology, children's type of disorder, and the culture of the area (including the public support system for developmental disorders).

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AUTHORS' INFORMATION

Full name: Yutaro Hirata
Institutional affiliation: Kagoshima University (Japan)
Institutional address: 1-21-30 Korimoto, Kagoshima 890-0065, Japan
Short biographical sketch: Yutaro Hirata (PhD) is an associate professor in the Faculty of Law, Economics, and Humanities at Kagoshima University. He is interested in the studies conducted by Japanese psychologists in the field of school and education and the characteristics of their participants, with particular interest in children with special educational needs and support for their families.

Full name: Yutaka Haramaki
Institutional affiliation: Hiroshima University (Japan)
Institutional address: 1-3-2 Kagamiyama, Higashi-hiroshima, Hiroshima 739-0046, Japan
Short biographical sketch: Yutaka Haramaki (PhD) is a Professor for the Psychological Program at Hiroshima University. He is a clinical psychologist who supports people with chronic physical disease (e.g., hemodialysis patients) and developmental disorders (e.g., autism spectrum disorder) using Dohsa-hou (Japanese original psychotherapy), and is also a mentor at the Developmental Disabilities Support Center.

Full name: Yasuyo Takano
Institutional affiliation: Aichi Shukutoku University (Japan)
Institutional address: 2-9 Katahira, Nagakute, Aichi, 480-1146, Japan
Short biographical sketch: Yasuyo Takano (PhD) is an associate professor in the Faculty of Psychology at Aichi Shukutoku University. She is a clinical psychologist who provides psychological support to people with severe disabilities and their families. She is also interested in adolescent psychological challenges and support, and is conducting research on the effects of therapy dogs using physiological indicators.