

Becoming Autonomous Parents in Giving Intervention to Children with Autism *Is It Possible?*

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Abstract: Children with autism spectrum disorder (ASD) need intervention to deal with social interaction difficulties. However, the fact that intervention may cost a lot of money on the one hand and that parents have potentials to overcome their difficulties on the other hand has inspired initiative to involve parents in giving intervention to children with ASD. Studies have shown that parent training, social skill training group, and cognitive behavioral therapy are useful and promising intervention strategies for improving children's social skills. This study was aimed at studying the effectiveness of parent training in improving of parents' skills and independence in designing and implementing the individualized social skills intervention program and the effectiveness of parental independent intervention in improving children with ASD. This study was carried out in two phases involving two group of subjects: parents in the training phase and children in the intervention phase. The results showed that the independent intervention program was effective in improving the parents' skills and independence in designing and implementing the individualized social skill intervention program and that parental intervention was effective in improving the social skills of his child diagnosed with ASD.

1 INTRODUCTION

Autism spectrum disorder (ASD) frequently affect negatively social skills. This has caused children diagnosed with ASD a lot of problems in their school, social, and work environments. As a result, they lack confidence, have low self-esteem, feel anxious and depressed, and have mental difficulties. Low social skills also make them prone to bullying. Therefore, children with ASD need early and intensive intervention. Early, intensive, and proper intervention will help them improve social skills (Stone and DiGeromino, 2014). However, therapy may cost them a lot of money. Jarbrink et al. (2006) suggest that autism intervention requires substantial amount of money. Similarly, according to Wang et al. (2013), children with ASD need an intensive and long-term treatment, so the cost becomes greater than that of other disorder intervention. In this regard, Poling and Edwards (2014) said that in developed countries expensive education is often protested because it only benefits some children. Many advocacy groups, such as Autism Speaks, The Autism Advocacy Network, Autism One, Moms on a Mission for Autism, and

Unlocking Autism, are lobbying for politicians to provide financial support for research and autism treatment.

A study conducted by Kim et al. (2011) in South Korea showed that two-third of ASD cases of research sample taken from a population in general schools were undiagnosed and untreated. A study by Salomone et al. (2015) on parents in 18 European countries showed that in several countries 64% of children with ASD had never received intervention at all, 64% received speech and language intervention, and 55% received intervention of relationship, development, and behavior. Howell, Lauderdale-Littin, and Blacher's (2015) study revealed that 94% of parents who became the respondents were helpless in finding intervention for their children because their ignorance of the availability of such services.

In Indonesia, autism therapies are not affordable by all. As suggested by the chair of Indonesia Autism Foundation, Melly Budhiman, a one hour autism therapy costs about IDR 50K to 250K. Ideally, autistic children need a four hour therapy a day. Assuming that a one hour therapy costs IDR 75K, a month of therapy will cost IDR 7.5 million or around USD 555 (Media Indonesia Epaper, 2014).

The above explanation shows that it is not easy for children with ASD to get intervention, but there is no excuse for not giving them early intervention.

2 PREVIOUS STUDIES

Previous studies showed that parents could be a reliable resource for early intervention. Parent participation plays an important role in the giving of intervention to children with ASD (Negri and Castorina, 2014; Elder, 2013; Shie and Wang, 2007) and makes therapy effective and low-cost (Rudy, 2013). The philosophy of treatment in the family context is to develop the children optimally by giving them family-centered early intervention (Iversen, et al., 2003). The family-centered early intervention aims at improving baby and early childhood development and minimizing the potentials for developmental delays through increasing family capacity in dealing with baby and children with special needs (Dunst, Bruder, and Espe-Sherwindt, 2014). This aim indicates that parents should be sufficiently competent in giving effective early intervention.

Effective early intervention has encouraged parent training so that the parents can treat their children at home. Studies have shown that parent training, social skill training group, and cognitive behavioral therapy are useful and promising intervention strategies for improving children's social skills (Autism Ontario, 2012). Some studies have shown the advantages of empowering parents in giving autism intervention; among others are: facilitating generalization and skill maintenance and cost-cutting (Relate to Autism, 2010), decreasing parents' stressor and increasing optimism (McConachie and Diggle, 2007), parents can manage their life, solve problems, and make decisions effectively (Shie and Wang, 2007), parents become skillful in implementing their newly learned skills (Beaudoin, Sébire, and Couture, 2014), and providing prognosis and better long-term quality of life (Elder, 2013; de Bruin et al., 2015).

However, the common weakness of the implementation of the offered training programs is that the parents are only trained to implement intervention program designed by professional therapists. Studies have revealed that: 1) the professionals in parent training program is frequently viewed as well-trained experts in giving intervention, so they act as the decision makers in designing education for children with special needs, and the parents only act as passive information receivers, 2)

the professionals are too dominant in the parent empowering program, 3) the program is clinician-oriented and sometimes does not meet the family needs, 4) some parents find difficulties in giving intervention to their children (Shie and Wang, 2007). Korfmacher et al. (in Dunst, Bruder, and Espe-Sherwindt, 2014) suggest that many models and approaches to engage parents in early intervention program are done as a part of home visit program of professionals who provide support and training to parents in improving their children development. Özdemir (2007) argues that to consistently focus on parent participation, family service, and early intervention outcomes, early intervention practitioners should apply theories and home visit practice better.

Based on the aforesaid description, it could be said that in the existing intervention training, parents still rely on professional therapists in designing intervention program/curriculum and professional home visit plays an important role in the sustainability and the effectiveness of intervention. When confronted with the limited availability of professional therapists and the high cost of curriculum designing, this reliance will potentially hamper the sustainability of the intervention. On the other hand, there is no scientific evidence that parents can be sole intensive behavioral intervention providers for children with ASD (Tomaino, Miltenberger, and Charlop, 2014).

Therefore, it is necessary to design an intervention program that is not only beneficial for children development, but also can train parents' self-reliance in developing, implementing, and evaluation an intervention program. The self-reliance, the researchers assume, not only can make intervention effective and efficient, but also sustainable and responsive to the progress of the children.

The solution is to empower parents' self-reliance in designing and giving intervention to the children with ASD. There are two major things to train to the parents: conceptual understanding about ASD, social skills, intervention, and individual intervention program and practical skills in designing the program and techniques of individualized intervention. And the professionals train the parents' self-reliance through training, workshop, mentoring, and monitoring the implementation of intervention. In addition, parent empowerment should take into account the following aspects of adult people: (1) the need of parents to know what to train, why they should participate in the training, and how the training is implemented, (2) parents' concepts about their self-reliance and skills in the training, (3) parents'

background experience, (4) parents' readiness to participate in the training, (5) parents' motives in their participating in the training, and (6) parents' learning motivation (Knowles, Holton, and Swanson, 2005).

A well-designed and well-implemented empowerment program is expected to improve parents' self-reliance in designing, implementing, and evaluating social skill intervention program for

their children in accordance with the natural condition of their children and family. That way, the intervention will continue be sustainable and develop in accordance with increasing environmental demand for children. As a result, children's social skill will continue to develop in accordance with their needs.

In brief, the research framework is illustrated in Figure 1.

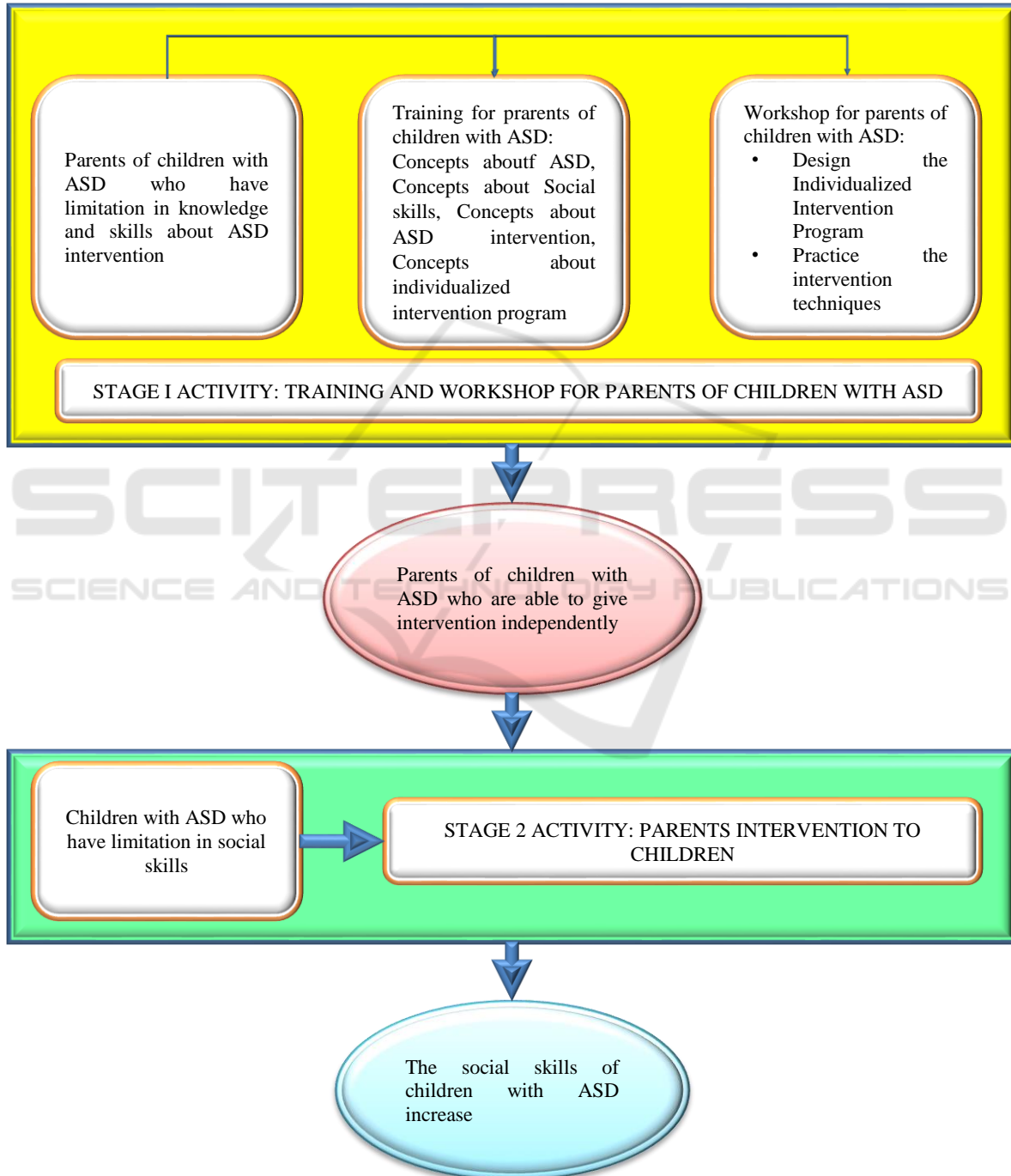


Figure 1: Research framework.

3 METHODS

The study was carried out using a quasi-experimental design. The use of this this design was: 1) test the effectiveness of training to improve parents' capability in designing individualized social skill intervention program for their ASD children and 1) to test the effectiveness of parental intervention to improve their ASD children's social skills.

The research subjects were 6 parents and their ASD children. The parents were chosen as the subjects based on the following criteria: 1) to have an ASD child, 2) to be able to read and write, and 3) to be willing to participate in the research. And the children were chosen as the subjects based on the following criteria: 1) to suffer from ASD with low and moderate severity and 1) to be 5-7 years old.

The research instruments were: 1) parents' self-evaluation questionnaire on their capability in designing the intervention program before and after the training, 2) assessment sheets of the intervention program contents prepared by the parents, and 3) observation sheets used by the parents to assess their children's social skills after the parental intervention. The children's social skills assessment was carried out every week during six weeks.

Data of parents' capability in designing the intervention program were analyzed quantitatively using Wilcoxon Signed Rank with significance level (α) of 0.05. The result of analysis of parents' self-evaluation data was used to figure out the effectiveness of training in improving parents' capability in designing the intervention program. The assessment by the researchers used a 1-3 scoring scale: 1 if the content of the program is not appropriate, 2 if less appropriate, and 3 if appropriate. Parents' mean scores were grouped into three: "Not Capable" if the mean score <1 , "Quite Capable" if the mean score = 1-1.49, and "Capable" if the mean score = 1.5-2. The result of researchers' assessment was used to enrich the data of parents' self-evaluation.

Data on children's social skills after parental intervention were analyzed qualitatively by seeing the frequency of social skills consistently displayed by the children per se every week. The assessment was conducted for six weeks. The social skill display frequency was divided into four, from the lowest to the highest: "Almost Never" if the children almost never displayed social skills trained by their parents, "Occasionally" if they displayed them at times, "Often" if they frequently displayed them in multiple places or occasions to certain people, and "Almost Always" if they consistently displayed them in

multiple places and occasions to many people. The success of parental intervention to their children was seen from the consistent frequency of social skills displayed by the children.

4 RESULTS AND DISCUSSION

4.1 Results

Based on parents' self-evaluation result, the parents' capability in designing the intervention program pre- and post-training can be seen in Table 1.

Table 1: Mean score of parents' capability in designing the intervention program pre- and post-training.

PRE	POST	GAIN
2.86	6.57	3.71

Table 1 shows that parents' capability in designing the intervention program improved after the training. Based on the non-parametric Wilcoxon Signed Rank test using the significance level of 0.05 by means of SPSS version 20, the difference was significant, 0.017 ($p < 0.05$). Since $p < 0.05$, so H_0 was rejected. In other words, the parents' capability in designing the intervention program improved significantly after the training. Therefore, it can be said that the training was proven to be effectively improve parents' capability in designing intervention program for their ASD children.

Table 2 presents the researchers' assessment score of the content of the intervention program.

Table 2: Mean score of parents' capability in designing intervention program based on researchers' assessment.

Subject	Mean Score	Category of Capability
1.	1.97	Capable
2.	2	Capable
3.	1.71	Capable
4.	2	Capable
5.	1.66	Capable
6.	1.8	Capable

Table 2 shows that all parents were capable of designing the intervention program appropriately. Assessment of the effectiveness of parental intervention is based on a parents' weekly assessment after the children received the intervention. The intervention data were obtained after the parents gave

interventions at least within 6 weeks. The parents recorded the consistent frequency of social skills displayed by their children by providing qualitative assessment: Almost Never, Occasionally, Often, and Almost Always. Table 3 shows that all children, on

every aspect of social skills, displayed improved frequency of social skills despite that the improvement took place in different weeks.

Table 3: Consistent frequency of social skills displayed by the children.

SUBJECT	SOCIAL SKILL ASPECTS	WEEK							
		0	1	2	3	4	5	6	7
1	Conversational skills	OC	OC	OC	OF	OF	OF	OF	-
	Play skills	OC	OC	OC	OC	OF	OF	OF	-
	Understanding emotion	OC	OC	OC	OC	OF	OF	OF	-
	Dealing with conflict	OC	OC	OC	OC	OF	OF	OF	-
	Friendship skills	AN	AN	AN	OC	OF	OF	OF	-
2	Conversational skills	OC	OC	OC	OC	OC	OF	OF	-
	Play skills	AN	AN	AN	AN	AN	AN	OC	-
	Understanding emotion	OC	OC	OF	OF	AA	AA	AA	-
	Dealing with conflict	AN	AN	OC	OC	OC	OF	OF	-
	Friendship skills	AN	AN	AN	AN	AN	AN	AN	-
3	Conversational skills	OC	OC	OC	OC	OF	OF	OF	-
	Play skills	OC	OC	OC	OC	OF	OF	OF	-
	Understanding emotion	OC	OC	OC	OC	OC	OF	OF	-
	Dealing with conflict	OC	OC	OC	OC	OC	OC	OC	-
	Friendship skills	OC	OC	OC	OC	OC	OC	OC	-
4	Conversational skills	OC	OC	OC	OC	OC	OF	OF	AA
	Play skills	OC	OC	OC	OC	OC	OF	OF	-
	Understanding emotion	OC	OC	OC	OC	OF	OF	OF	-
	Dealing with conflict	OC	OC	OC	OC	OC	OC	OF	OF
	Friendship skills	OC	OC	OC	OC	OC	OC	OF	OF
5	Conversational skills	OC	OC	OC	OC	OF	OF	OF	-
	Play skills	AN	AN	OC	OC	OC	OF	OF	-
	Understanding emotion	AN	AN	AN	OC	OC	OC	OC	-
	Dealing with conflict	AN	AN	AN	AN	OC	OC	OC	-
	Friendship skills	AN	AN	AN	AN	AN	AN	AN	-
6	Conversational skills	AN	AN	AN	AN	OC	OC	OC	-
	Play skills	AN	AN	AN	OC	AN	AN	OC	-
	Understanding emotion	AN	AN	AN	OC	OC	OC	OC	-
	Dealing with conflict	AN	AN	AN	AN	OC	OC	OC	-
	Friendship skills	AN	AN	AN	OC	AN	OC	OC	-

Note:

AN = Child almost never shows social skills behavior

OC = Child occasionally shows social skills behavior

OF = Child often shows social skills behavior

AA = Child almost always shows social skills behavior

Week-0 = social skills before intervention

Week-1 etc. = social skills after intervention

4.2 Discussion

Based on Table 4.1 and 4.2, it could be said that the training effectively improve the parents' capability in designing the intervention program in accordance with the needs and condition of their respective child and family. The parents were trained to design the individualized social skill intervention program by taking into account the factual condition and needs of

their children and family. The parents also received feedbacks about their prepared intervention program and were given opportunity to propose improvements to the program format so as to make it appropriate and easy to do. According to Kolb (2007), an effective training has several characteristics; among others are: to begin with assessment of parents' needs about training, parents are given opportunity to practice what they learn from training in a natural family

setting, parents get regular feedback from the trainer during the exercise, and parents are given opportunity to develop the skills acquired during the training. Referring to these characteristics, the training could be said effective to improve parents' capability in designing the individualized social skill intervention program. It was understandable that the parents found some difficulties at the early stage since they were not used to designing an intervention program for their own children. This is in line with the result of Shie and Wang's (2007) research that in parent empowerment training, the professional therapists are usually dominant in designing and developing an intervention program, and the parents act as passive information receivers.

Based on Table 4.3, it could be concluded that overall the parental intervention improved social skills of the children with both low and moderate ASD, and the improvement occurred in different periods among them. The result of this research is in agreement with that of Dunst, Bruder, and Espe-Sherwindt's (2014) research that parent participation in an intervention is a very important component in enhancing children's learning and development. In addition, this research also confirms the statement of Nefdt et al. (2010) that a natural intervention procedure is easy to be understood by the parents. A natural intervention procedure is an intervention procedure designed in such a way that it is relevant to family habits and values, done in an environment that the parents and children are familiar with, and using daily media and activities.

5 CONCLUSIONS

This study has concluded that generally the independent intervention program has successfully empowered parents in providing intervention to their children diagnosed with autism spectrum disorder. Elaborately, this study has concluded the followings:

First, the independent intervention program was effective in improving parents' understanding about ASD, social skills, intervention, and individualized social skills intervention program for children with ASD.

Second, independent intervention training and workshop program was effective in improving the affective function of parents of children with ASD.

Third, independent intervention workshop program was effective in improving parents' skills in designing individualized social skills intervention program for their children diagnosed with ASD.

Fourth, generally the parents were quite independent in designing the individualized social skills intervention program for children with ASD.

Fifth, generally the training and workshop improved the parents' skills in implementing the social skill intervention for their children diagnosed with ASD.

Sixth, the parental intervention with reference to the individualized social skills intervention program developed by the parents was effective in improving the social skills of children with ASD.

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