

Family intervention program for autism

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Abstract

Interventions can minimize the impact of developmental barriers on autism. Inconsistent interventions result in behavioral deterioration. Parents have a big role to provide consistent intervention to children. This study aims to review home intervention programs that family can do at home. The research method used is a literature review. The data collection method used is the literature related to home-based autism interventions and family intervention. The results of the study show several programs that can be applied by families at home. The results showed the intervention models that can be done by family are ABA, PLAY, dan TEACCH. Through this study, it can be concluded that ABA is the most effective technique that can be used as a basis for implementing family interventions. Comprehensive interventions are also highly recommended for home interventions, such as modifying the environment and providing preschool life skills.

Keywords: Autism, home intervention, program intervention, parent, family intervention

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Introduction

Children with autism have several barriers, repetitive behavior (repetitive behavior), playing alone with the world, really likes certain objects to be difficult to separate, and does not like changes in the environment or routine (Mangunsong, 2009). This change causes the child to become prone to tantrums. In addition, children also have obstacles with aggressive behavior and are difficult to obey. Giving intervention is needed for children from an early age.

Currently, parents of children with autism have difficulties. The pandemic situation has resulted in children not getting the usual interventions found in schools or therapeutic institutions. Many therapeutic institutions for autistic children are closed due to the COVID-19 pandemic. Several articles also mention that parents of children with autism are experiencing difficulties due to the pandemic. Families with children with autism in the United States also face difficulties as schools and services close. The United States also produced a survey where 82% of parents said that the COVID-19 pandemic had affected children's mental and emotional health (Ansori, 2020).

Autistic parents in Pati City are also worried because therapy services for children have stopped. According to Haryanto as the Regent of Pati said that it can be anticipated by conducting therapy training for parents so that it can be carried out at home (Achmad, 2020). The absence of intervention received by students during the Covid-19 pandemic resulted in behavioral problems in autistic children appearing more often (Colizzi et al., 2020). In addition, families also feel stressed due to the pandemic because they have to care for and provide interventions for children for 24 hours, longer than the usual time (Manning,

Billian, Matson, Allen, & Soares, 2021). Stress experienced by families because they do not know and are not used to providing intervention to children with autistic barriers.

Based on preliminary studies that have been carried out, some parents contact teachers or therapists to ask when therapy is started, then complain that there is a lot of regression or behavioral deterioration in children, such as lack of compliance. Parents said that the previous therapy, which had progressed upwards, was in vain because at this time there were many setbacks. Regression or deterioration of behavior experienced by autistic children is caused by inconsistent therapy.

Giving interventions to children requires consistency from those around them, but currently there are still many parents who have not implemented interventions at home. The intervention was given in schools and therapy institutions, but when at home, parents did not provide intervention. This inconsistency makes student development less than optimal. The role of parents is very important in providing interventions because handling autistic children takes a long time, and really requires the role of parents of children (Handojo, 2003).

The need for consistent intervention is a prerequisite for effective implementation of the intervention. Giving intervention to children requires consistency from everyone around including parents. This is in accordance with the opinion (Handojo, 2003), that handling autistic children takes a long time, and really requires the role of the child's parents. Parents are the closest people to optimizing interventions for children with autism (Malucelli, Antoniuk, & Carvalho, 2020). Parents can implement interventions in daily activities and optimize child development.

Family-centered interventions have a positive effect on improving social interaction skills (Park, Park, Yoo, Han, & Galeoto, 2020). Interventions that involve parents will also help parents who are economically disadvantaged to take their children to a therapist institution that costs money. Parents have a role to prepare and involve themselves in child interventions as well as planning treatment or family-centered interventions (Gentles, Nicholas, Jack, McKibbon, & Szatmari, 2020).

The involvement of parental intervention in the application of therapy at home will help children get consistent interventions. In addition to children receiving therapy in schools and therapy institutions, the application of therapy at home will also help the effectiveness of the intervention (Rutherford et al., 2019). According to (Handojo, 2003), the implementation of therapy should be carried out for 40 hours in 1 week. Based on this opinion, the implementation of therapy is not only done in schools or in therapeutic institutions, but also must be done at home. In addition, Handojo also said that to get maximum results, the application of therapy must be done from the time the child wakes up. Parent-centered interventions show effective results, hence the need for further research on the role of parents as an intervention model (Rutherford et al., 2019). The purpose of this study is to review the interventions that families can provide for children with autism.

Method

The type of method used in this study is a literature review. The sources used are relevant international articles related to interventions carried out by families or parents at home. Then through the results of the study, analyzed systematically so that it can contain relevant information. The databases that are the source of this literature are Scimago Journal Rank, and Google Scholar. The literature study used is articles in English. In the Scimago Journal Rank, searched using the keyword autism. Several journals that appeared were the Journal of Autism and Developmental Disorders, Autism, Research in Autism Spectrum Disorder, Focus on Autism and Other Developmental Disabilities, Education and Training in Autism, and Autism and Developmental Language Impairments. In each journal and on Google Scholar, the keywords are intervention, autism therapy, parent intervention, family intervention, home based intervention, autism home intervention and home intervention. The description of the abstract helps to determine whether it meets the requirements for entry into the literature. The list of literature that has been searched will be checked and identified.

The criteria for selecting the study are a) The year of publication of the article in 2012-2021, b) written in English, c) the intervention process for autistic children is given by father, mother, parents or family, d) Research focuses on improving children's abilities, e) Research using this type of quantitative

research. Then some of the characteristics that made the article not included from the literature list are a) the method is not explained, b) the research focuses more on training interventions for parents by experts or professionals in order to apply interventions to children, c) methods using a systematic review or meta-analysis.

Results and Discussions

The article search process resulted in 98 articles with appropriate titles. Furthermore, the article is reviewed by paying attention to the abstract and the entire article briefly. Articles are selected according to the criteria. Articles that meet the criteria are 25 articles. 72 articles were omitted from the literature list due to some incongruous characteristics, particularly with respect to the study design and intervention provider. The research method used from the 25 articles is quantitative (generally with pre-test, post-test and experiments with several research models such as SSR, multiple baseline design. Description of study characteristics and family intervention programs in more detail is shown in Table 1.

Table 1 <Characteristics of Family Studies and Intervention Programs>

Name and Year of Research	Research design	Participants	Intervention Provider	Type of Intervention	Aspek Peningkatan pada Luaran Intervensi (Outcome)
(Flippin, 2019)	Research subjects with multiple baseline	1 child with ASD (age 37 months boy)	Father	Responsive strategy	Improved expressive language skills and decreased parental stress
(Valeri et al., 2020)	Randomized controlled trial	34 participants (7 women, 27 men, aged 2, 6, 11 years)	Parent	LPI (low-intensity psychosocial intervention)	Increase social interaction and reduce parental emotion and stress
(Malucelli et al., 2020)	Experiment	18 children (9 SG, 9 CG): 29-42 months old	Parent	ESDM (Early Start Denver Model)	Improve receptive language skills, expressive language, social skills, behavior and independence
(Park et al., 2020)	Single Subject Design	3 ASD children (aged 29-36 months)	Parent and Nanny	Provides a sensory apparatus, reduces unnecessary visual and audio stimuli, provides individual space, provides vestibular and proprioceptive stimulation	Improve social communication skills and reduce parental stress levels
(Dogan et al., 2017)	Multiple baseline design	4 children and their parents	Parent	Behavioral training	Improve social skills

Name and Year of Research	Research design	Participants	Intervention Provider	Type of Intervention	Aspek Peningkatan pada Luaran Intervensi (Outcome)
(Delemere & Dounavi, 2018)	Quantitative, <i>multiple baseline across subject design</i>	6 participants, 2-7 years	Parent	ABA (Applied Behavior Analysis) on Bedtime Fading and Positive Routines 20hours/week	Increase sleep and positive routine
(Gunning, Holloway, & Grealish, 2020)	Experiment	13 children, 6 children (3 yrs 3 mth-4 yrs 11 months) and 6 children (3 yrs 11 mths-6 yrs old)	Parent	PLS (Preschool Life Skill)	Improve preschool life skills and reduce behavior problems
(Strand & Eldevik, 2017)	Single Subject Research	1 child	Parent	EIBI (Early Intensive Behavior Intervention)	Reduce behavioral problems
(Haraguchi et al., 2020)	Experiment	27 children (SG) and 34 children (CG)	Parent	Low Intensity Behavioral Interventions with CPMT	Improve children's language and social skills
(Tal-Atzili & Salls, 2017)	Pretest-posttest	Three children with their families (The study was conducted for 5 months), aged 26 months, 27 months, and 47 months	Parent	QST (Qigong Sensory Training) is a tactile intervention developed based on the principles of Chinese medicine with 12 steps of tactile intervention	Improve sensory processing: self-cleaning activities, improve eye contact, social skills, expressive and receptive language, increase attention reduce the frequency and intensity of walking on the toes Reduce stress on parents

Name and Year of Research	Research design	Participants	Intervention Provider	Type of Intervention	Aspek Peningkatan pada Luaran Intervensi (Outcome)
(Sanefuji & Ohgami, 2013)	Experiment (1 group was given the intervention, the other 1 group was not given the intervention)	16 children-japanese mother (14 boys and 2 girls)	Mother	“Being-imitated” strategy The mother in the imitation state is instructed on how to imitate all of her child's behavior, including facial expressions and meaningless speech.	Increase eye contact and attention to others
(Pennefather, Hieneman, Raulston, & Caraway, 2018)	Pre-post test with three weeks of intervention	23 children aged 4 to 8 years and their parents (16 parents who have completed the post-test)	Parent 21 mothers and 2 fathers	ABA (Applied Behavior Analysis) and stress reduction strategies for parents	Reduce parental stress Increase parental knowledge Improve children's social skills Reduce hyperactive behavior
(S. T. Liao et al., 2014)	Pre-post test with 10 weeks of intervention	11 children aged 45-69 months with their mother	Mother	Home based-DIR/ Floor time Intervention Program	Increase social interaction Improve adaptive behavior (communication and daily life skills) Increase interaction between parents and children
(Mahoney & Solomon, 2016)	Experiment (1 SC group, and 1 SE group)	148 families, but only 128 families met the criteria, and only 112 did the full study	Family	PLAY (Play and Language for Autistic Youngsters)	Improve the ability to interact between children and parents
(Smith, Klorman, & Mruzek, 2015)	Quantitative	71 children who received EIBI intervention	Family	EIBI (Early Intensive Behavioral Intervention)	Improve social skills (social approach, attention, and imitation) Improve adaptive behavior

Name and Year of Research	Research design	Participants	Intervention Provider	Type of Intervention	Aspek Peningkatan pada Luaran Intervensi (Outcome)
(Solomon, R., Van Egeren, L. A., Mahoney, G., Quon Huber, M. S., & Zimmerman, 2014)	Experiment (1 group was given the intervention, the other 1 group was not given the intervention)	128 children with autism aged 2 years 8 months to 5 years 11 months	Parent	Play Project Home Consultation Intervention Program	Increase social interaction Reduce autism symptoms
(Welterlin, Turner-Brown, Harris, Mesibov, & Delmolino, 2012)	Pre-post test	20 children 2 to 3 years old	Family	TEACCH	Improve activity or work skills (behavior of carrying out activities) Increase independence
(Hutchins & Prelock, 2013)	Multiple baseline design	20 children with autism ages 4 to 12	Family	Social Stories	Improve communication Improve behavior
(Lindgren et al., 2016)	Experiment (1 group was given the intervention, the other 1 group was not given the intervention)	107 children with ASD or DD.	Parent/Grandfather and grandmother	ABA (Applied Behavior Analysis)	Reduce behavioral problems
(Mueller & Moskowitz, 2020)	Pre-post test	3 kids with family	Family	Combination of CBT and positive intervention	Reduce behavioral problems
(Siller, Hutman, & Sigman, 2013)	Experiment (1 group was given the intervention, the other 1 group was not given the intervention)	70 children with parents	Parent	FPI (Focused Playtime Intervention)	Improve communication
(Sood, LaVesser, & Schranz, 2014)	Quantitative, correlational research	22 children with autism disabilities	Family	Home Environment	Improve the ability to work at home

Name and Year of Research	Research design	Participants	Intervention Provider	Type of Intervention	Aspek Peningkatan pada Luaran Intervensi (Outcome)
(Masse, McNeil, Wagner, & Quetsch, 2016)	Kuantitatif, single subject research	Three families with children with autism aged 2 to 7 years	Family	PCIT (Parent Child Interaction Therapy)	Reduce behavioral problems
(Thompson, Mcferran, & Gold, 2014)	Experiment (1 group was given the intervention, the other 1 group was not given the intervention)	23 children with autism aged 36-60 months, 12 children were given additional FCMT intervention, and 11 children were given only initial intervention	Family	FCMT (Family Centered Music Therapy)	Increase social interaction in the surrounding environment, and the relationship between parents and students
(Bradshaw, Koegel, & Koegel, 2017)	Quantitative, multiple baseline design	Autism aged 15 to 21 months	Parent	Pivotal Response Treatment Program	Improve verbal communication

Various types of interventions that can be applied by families for children with autism barriers. Interventions have different goals, there are goals that are single goals and complex goals. Several interventions that have a single goal are QST (Qigong Sensory Training), Being imitated strategy, and Pre-School Life Skills. These strategies can be used as interventions whose objective is only to focus on one short-term or long-term goal. QST can be used as a useful tactile intervention to improve sensory processes such as reducing the intensity of walking using the toes (Tal-Atzili & Salls, 2017). Then there is "Being imitated strategy" where people around imitate or imitate all children's behavior, including facial expressions and speech (Sanefuji & Ohgami, 2013). Such interventions can increase the child's eye contact and attention to others.

Autism has complex developmental barriers, especially in communication, social interaction and behavior (Association, 2013). Complex developmental barriers require interventions that can improve several aspects of autism. Several interventions that can improve autism ability in several aspects are ABA (Applied Behavior Analysis), PLAY, TEACCH, and environmental modification.

Some parents use the ABA technique as the basis for implementing the intervention. The ABA technique is applied to several family interventions. Parents can directly apply pure ABA interventions (Lindgren et al., 2016; Pennefather et al., 2018) or can apply ABA techniques as the basis for interventions, such as ESDM (Malucelli et al., 2020), behavioral training (Dogan et al., 2017), bedtime fading (Delemere & Dounavi, 2018), EIBI or Early Intensive Behavior Intervention (Smith et al., 2015; Strand & Eldevik, 2017), and Low Intensity Behavioral Interventions (Haraguchi et al., 2020).

ESDM intervention is based on ABA or behavioral analysis. The intervention procedure in ESDM is that parents apply ABA techniques to routines and play activities (Malucelli et al., 2020). Second, behavioral training also applies ABA as the basis for implementing interventions (Dogan et al., 2017). The procedure for implementing behavioral training is by providing examples of social skills, imitation

processes, role playing, feedback by parents, additional training, re-examination of children's abilities, post-training and follow-up of the results after 1 month of completion of the training phase.

Then, the third is fading at bedtime (Delemere & Dounavi, 2018). Parents provide bedtime fading and positive routines on the basis of applying ABA. Parents do the fading of sleep time, namely the first by calculating the average sleep time and adding 30 minutes. Parents are advised to prevent bedtime before bedtime. If the child wakes up in the middle of the night, the child should be given instructions to return to bed every 30 minutes.

Next is a positive routine before going to bed, namely doing sleep readiness activities such as getting dressed, washing teeth, and telling stories by parents to children. Each activity must be done every night, the sequence and time must be appropriate every day, avoid challenging activities, and avoid looking at screens, such as cellphones and television. Parents are also required to provide intervention by presenting a series of schedules visually, so that parents can point when the schedule is for certain activities (Delemere & Dounavi, 2018).

The application of the next intervention that uses ABA as the basis for intervention is EIBI (Early Intensive Behavior Intervention) (Smith et al., 2015; Strand & Eldevik, 2017). The intervention process with functional communication exercises, responds to simple communication and provides feedback by parents when children take certain actions (Strand & Eldevik, 2017). Next is Low-Intensity Behavioral Interventions. Interventions using ABA principles and techniques such as reinforcement, encouragement, formation, task analysis, and sequences with several approaches, namely practice, visual strategies, and occupational therapy (Haraguchi et al., 2020).

Through several interventions that have been carried out by parents, the ABA technique is the most widely used technique as the basis of intervention (Delemere & Dounavi, 2018; Dogan et al., 2017; Haraguchi et al., 2020; Lindgren et al., 2016; Malucelli et al., 2020; Pennefather et al., 2018; Smith et al., 2015; Strand & Eldevik, 2017).

The ABA technique is a complex intervention and also has very complex benefits. Giving ABA interventions can improve intellectual abilities, communication, receptive language, adaptive behavior, socialization skills, and life skills (Makrygianni, Gena, Katoudi, & Galanis, 2018).

The improvement in the ability of the ABA technique is also shown by the improvement implemented from several interventions based on the ABA technique. The first is ESDM, there is an increase in aspects of receptive language, expressive language, social skills, behavior and independence (Malucelli et al., 2020). Second, on behavioral training. This intervention improves social skills in children. The third is fading sleep time and positive routines. These interventions increase children's sleep time and the formation of positive routines before bed in children (Delemere & Dounavi, 2018). Fourth is EIBI. EIBI can reduce behavioral problems (Strand & Eldevik, 2017). The fifth intervention is Low Intensity Behavioral Interventions (Haraguchi et al., 2020). This intervention is beneficial for children's language and social development.

The improvement in each aspect is adjusted to the intervention that has been given to the child. The ABA technique applied to children has more complex improvement outcomes such as receptive, expressive language skills, social skills, behavior, and independence (Makrygianni et al., 2018; Malucelli et al., 2020). ABA can also shape desired behavior and reduce behavioral problems (Delemere & Dounavi, 2018; Haraguchi et al., 2020; Strand & Eldevik, 2017). Furthermore, there are several interventions that also have certain intervention outcomes according to the intervention procedures carried out (Flippin, 2019; Gunning et al., 2020; Park et al., 2020; Valeri et al., 2020).

Giving intervention by parents at home can be done optimally, namely by applying the ABA technique in order to get more complex benefits (Makrygianni et al., 2018; Malucelli et al., 2020). Interventions can use the ABA technique as a basis for more effective interventions. The ABA program is an effective program and emphasizes parental involvement (Y. Liao, Dillenburger, He, Xu, & Cai, 2020).

The second intervention that improves complex abilities is PLAY (Play and Language for Autistic Youngsters). Three studies used this intervention as an intervention that can be administered at home by the family (S. T. Liao et al., 2014; Mahoney & Solomon, 2016; Solomon, R., Van Egeren, L. A., Mahoney, G., Quon Huber, M. S., & Zimmerman, 2014). The PLAY intervention was carried out by

involving children in play sessions of 15-20 minutes and throughout the daily routine for a total of 2 hours/day (Mahoney & Solomon, 2016). The PLAY intervention can also be used as the basis for providing interventions such as Home-based DIR/Floor Time (S. T. Liao et al., 2014). PLAY intervention can improve communication, social interaction and attention level.

The third intervention is TEACCH. TEACCH interventions can use social stories as a medium when providing interventions (Hutchins & Prelock, 2013). Giving TEACCH intervention can improve communication, behavior, and activity skills (Hutchins & Prelock, 2013; Welterlin et al., 2012). Interventions using the TEACCH approach were carried out in several studies to provide interventions for children with autism that were carried out by families (Hutchins & Prelock, 2013; Welterlin et al., 2012). The intervention applied is to provide an activity routine consisting of a chain of behaviors to take, complete, and store activities in a left-to-right order (Welterlin et al., 2012).

The fourth intervention is environmental modification. Some of the procedures carried out are by providing facilities that support children so that they can intervene, such as sensory devices, then inviting children to watch videos to shape children's behavior, reducing unnecessary visual and audio stimuli, providing individual space, and providing stimulation. vestibular and proprioceptive (Park et al., 2020). The availability of adequate toys and learning materials greatly improves children's ability to interact at home, in addition to a play area that is suitable for children's needs can improve students' sensory experience (Sood et al., 2014).

The ABA, PLAY, and TEACCH interventions are some of the approaches that can be taken at home when providing interventions for autism. Some of these approaches have complex benefits so that they are suitable for children with autism. Parents can also combine the previously described interventions with environmental modification interventions (Park et al., 2020) and the establishment of Preschool Life Skills (Gunning et al., 2020). Providing a comprehensive intervention will help children develop optimally.

Parental involvement in child intervention at home is very important and provides benefits. Providing interventions that involve parents can also reduce emotional levels in parents and reduce parental stress levels (Flippin, 2019; Park et al., 2020; Valeri et al., 2020).

Conclusions

The application of ABA, TEACCH and PLAY techniques can be used as the basis for implementing interventions by families for autism. The child's ability will increase in several aspects of development, such as language skills, behavior, social skills, and daily living activities. Comprehensive interventions are also highly recommended for home interventions, such as modifying the environment and providing preschool life skills. Environmental modification can be useful for creating an environment that can support children in implementing interventions and optimal child development. The provision of preschool life skills is intended so that children can prepare their abilities before school, because in general children have not received other interventions before school, so parents have a very large contribution to the application of preschool life skills.

The involvement of parents in the intervention greatly helps the effectiveness of the child's intervention process. In addition, the emotional level and stress level of the parents decreased due to the parents being directly involved in the child's intervention.

Interventions carried out by the family must be carried out. Family is someone who is very close and has the longest time together. Therefore, the family must also provide comprehensive interventions according to the needs of the child, namely providing training or direct treatment (providing interventions by sitting together or doing certain activities according to the intervention), always inviting communication and socializing, stimulating children to carry out daily activities independently. independently, providing preschool life skills training, as well as providing facilities according to children's needs (intervention tools or media, special rooms for learning, and so on). Providing a comprehensive intervention will also improve the child's ability in aspects of its development.

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