

**CASE REPORT:**

**PARENT TRAINING PROGRAM FOR AUTISM SPECTRUM  
DISORDER DURING THE COVID-19 PANDEMIC PERIOD IN  
INDONESIA**

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**ABSTRACT**

Autism Spectrum Disorder (ASD) is a pervasive developmental disorder that shows difficulties in communication, social interaction, behavior, interests and activities that are limited and repetitive. The prevalence of ASD also continues to increase worldwide, followed by an increase in the need for early intervention in ASD children. The limited services available make early intervention a challenge in itself. The long Covid-19 pandemic has resulted in limited therapy, because therapy in treatment service facilities cannot be carried out as before. In this case it is important to involve parents as the primary caregivers for ASD children in interventions to anticipate the limited interventions due to a pandemic situation. Parent Training can be done as an effort to provide information, education, and skills to parents so that they can provide intensive, comprehensive, sustainable, and early intervention.

**Keywords:** Parent, Autism, COVID-19, Indonesia

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## INTRODUCTION

Autism Spectrum Disorder (ASD) is known as pervasive developmental disorder which is a group of heterogeneous neurodevelopmental syndromes characterized by disorders in social communication, limited and repetitive behavior, and the development and use of distorted language [1]. Individuals with ASD will need lifelong support from various sources namely families, especially parents, teachers, and health service providers who have a large role [2]. A 2012 review by WHO estimated that the global prevalence of ASD was around 1%, whereas a more recent study estimated the prevalence was 1-5% in developed countries [2]. ASD is also found four times more often in boys than girls [1].

Caring for children with ASD is a challenge for families. ASD can have an impact on several areas of function life, and family welfare and increase negative health and social impacts on the family. In addition, studies show that quality of life in families with ASD is worse compared to families of children with ADHD. The symptoms that occur in ASD children along with other problems that accompany will have a significant impact on ASD children and their families in various ways depending on the nature, severity, frequency, and the number of symptoms and problems that accompany it. Caring for children with ASD and the severity of ASD symptoms will affect the mental and social health of patients and families such as anxiety, depression, isolation and social consequences, financial care, parental stress, family cohesion, relationship satisfaction, and lower well-being and high family conflict [3]. The relationship between child behavioral symptoms and family function is two-way, where challenging behavior for ASD children can worsen maternal well-being and in turn have a negative impact on children who inadvertently encourage reactive challenging behavior. The multiple impacts of ASD emphasize the need for management that is intense, sustainable, and comprehensive, involving active discussions with parents and coordinating support and guiding families towards appropriate interventions. However, currently there are still many limitations in the availability of services and coordination of existing care, so the provision of appropriate services and effective interventions is required. Interventions for ASD children who have a higher frequency, nature, and severity of symptoms in this regard need more intensive attention.

The appropriate interventions for individuals with ASD vary widely. The main goals of ASD management are to

increase social interaction, communication, correct deviant behavior, and improve long-term skills in living independently. The demand for special services for ASD children has increased as the prevalence of ASD has increased, so that service providers are expected to provide high-quality interventions as early as possible in the form of public services, equitable and accessible to all children with ASD in need. However, due to insufficient resource constraints, more children and parents are not able to get the services they should, and this is related to high levels of stress and psychological pressure [4].

The Covid-19 pandemic situation that has lasted for several months has resulted in therapy services being unable to be carried out as before, due to limited therapy in health care facilities due to social restrictions to prevent the spread of the Covid-19 virus. This is a form of limited availability of health services that arise due to special conditions. ASD children who are accustomed to routine therapy in health care facilities are unable to attend therapy as usual. This will result in ASD children who have experienced improvement in symptoms and have acquired skills in previous therapy, potentially reappearing symptoms that had previously improved, or losing their acquired skills.

Parents as primary caregivers of children and people who spend the most time with children. Parents can teach social communication skills that have been taught through practice to their children over time in various environments. This intervention strategy saves time and money [5]. Parents can also take on the role of coach or therapist in various interventions. The existence of the severity of certain symptoms can be one of the factors that influence parental stress. Furthermore, high parental stress levels can hamper the effectiveness of interventions in ASD children. Depressed parents result in less responsiveness of parents during play, which is associated with decreased child involvement, social interaction, social emotional functioning, delayed language development and mutual attention, low expectations of treatment and early discontinuation of therapy [4]. The severity of symptoms also increases when the demands in a particular environment exceed the individual's capacity to function at the required level [6].

The Parent Training Program is a training effort that aims to help parents teach children skills, manage, manage problematic behaviors and emotionally improve the quality of parent-child relationships. Existing studies comparing Parent Training (specific strategies for managing disruptive behavior) with Parent Education (information about autism but no

behavior management strategies) in parents of ASD children, the results show that the Parent Training Program is superior to parental education in reducing disruptive behavior [4]. The Parent Training Program is expected to be included as part of a comprehensive intervention on ASD children [7]. This is due to the high prevalence of ASD, making it difficult for families to access the intensity of interventions needed for the best results, so training parents to implement interventions can help optimize the intensity of interventions and their effects can be generalized and sustained over time, children may receive more interventions because more time with parents, and last longer. Apart from that, this training can also positively influence a child's development while reducing parental stress levels [5].

A meta-analysis study supports the effectiveness of parent training and is ready for wider implementation in a variety of settings. The increasing prevalence of ASD highlights the strong need for easily accessible and cost-effective care. Parent Training will teach parents specific techniques to manage behavioral problems in ASD children [8]. The current parent training program is considered an important component of a successful intervention program. This intervention is expected to be an option to facilitate services, especially in special situations such as the current pandemic that requires everyone to do physical and social distancing so that patients cannot undergo therapy as usual days. Through parental involvement, it is hoped that parents can implement therapy without having to attend service facilities. The distribution of appropriate interventions through parent training is also considered to be more cost effective. It can also increase family satisfaction and reduce parental psychological stress.

## CASE REPORT

A boy, aged 3 years and 2 months, came with his mother to the Children's Day Care Polyclinic Dr. Soetomo to undergo routine control of medication and behavior therapy that has been done since 4 months ago. The patient first went to the Psychiatric Hospital of dr. Soetomo, for a referral from the ENT Poli, complained that the patient was often hitting, banging his head or chin since 6 months ago. Previously patients were routinely controlled at the ENT Poli to undergo speech therapy because the patient complained of being unable to speak. Initially when he was 2 years old the patient could speak a few words, but after 2.5 years the patient did

not speak anymore. Patients also did not respond at all when summoned since they were 2.5 years old, seemed indifferent and tended to be busy themselves. Patients also actively play alone and cannot stay still. Patients sometimes want to join their friends to play, but only a short time later the patient leaves and is busy playing alone. Patients like to disturb their friends so that their friends also go away and don't want to play with patients. If you want something, the patient only points to the item or pulls the patient's mother's hand. Because he did not respond when he was called, the patient looked like he did not hear so the patient was then taken to the Puskesmas and referred to the ENT clinic at Unair Hospital because he was suspected of having hearing loss. The audiology test is said to be normal.

The patient has been routinely undergoing therapy and treatment at Daycare RS Dr. Soetomo since 4 months ago. In addition to undergoing therapy in Daycare, patients also undergo therapy at the Miracle Center. During therapy, the patient's development was quite good, the patient was able to say a few words such as "apple", "thank you", "mamam", rarely banging or banging his head, responding when called, even though he has to be called repeatedly and the response only a few seconds. However, since the Covid 19 pandemic occurred, the patient has stopped undergoing routine therapy, it has been around 1.5 months, due to temporary holidays, only undergoing therapy at Daycare 2 times a week. Since not undergoing therapy at the Miracle Center, according to his mother, the patient started hitting his head and banging his head again like before undergoing therapy. Some of the words that the patient has been able to pronounce are also no longer pronounced. According to his mother, the patient has been trained while at home, but the mother does not know for sure how patients are usually trained so they cannot practice it. On a daily basis, mothers usually invite patients to play puzzles, arrange blocks, or play colors with crayons.

The patient's mother is given Parent Training by providing information about concepts and interventions in children with ASD. After the parents understand the information, they are taught skills by actively involving parents in the exercises. The skills taught this time target the maladaptive behavior that exists in the patient and require immediate intervention namely beating or banging on the head or chin. The training method is carried out with a training package consisting of instruction, modeling, rehearsal, and feedback. Important concepts of intervention include directions to always invite children to communicate, provide stimulation

to stimulate children's responses, invite to play together, and actively invite to talk. Skills that target maladaptive behavior are carried out by distracting, when the child is about to hit or hit the head and chin, immediately say no, hold the child's hands and then divert to games such as playing balls or dolls that are not harmful. Previously, the child was introduced to the ball or doll to get mutual attention. This exercise is carried out by means of demonstrations and role play with the coach on one occasion. However, due to time constraints due to the pandemic situation, the sustainability of this Parent Training Program can be done through video modeling. Home practices between parents and children can also be videotaped and then sent to the trainer for feedback. Apart from information, education, and skills training, parents are also taught appropriate parenting strategies for ASD children. Parents are also taught to conduct clinical assessments, current assessments and decision making, as well as flexible teaching while applying a variety of behavior-based techniques.

## DISCUSSION

Children with ASD face challenges arising from their difficulties in understanding social behavior and interactions, difficulties in understanding and using communication effectively, and difficulties with reduced flexibility in thinking and behavior. There are various intervention approaches used for ASD children, which need to be adjusted to their background, not all children benefit equally from similar interventions and only a few studies have assessed the response to interventions undertaken [4]. The demand for interventions for ASD children has increased as the prevalence of ASD has increased, so that the existing services are expected to provide high-quality interventions as early as possible in the form of public services, equitable and accessible to all ASD children in need. However, in the case above, in the covid-19 pandemic situation it causes its own obstacles, so that the patient has not been able to get the proper service, which can have an impact on the patient's condition and is related to the level of stress and psychological pressure on the parents.

Studies show a significant role for parenting strategies to manage and prevent maladaptive behavior in ASD children. This shows the importance of quantitative and qualitative appropriate parenting strategies and more complex parental participation in ASD children. In this case, positive parenting, involvement, supervision and monitoring,

consistency and discipline from parents are needed. Some of the parenting strategies that can be identified include accommodating children, modifying the environment, providing structure, routine and work, supervision and monitoring, managing non-compliance with daily tasks and activities, responding to problem behaviors, managing difficulties, maintaining security, analyzing and planning [9]. Higher levels of negative care can aggravate behavioral problems later in life and lower levels of negative care can be protective of behavioral problems for ASD children, so it is important to imply interventions involving parents and target care for ASD children [10]. In the Parent Training Program given to the patient's parents in the case above, includes the concept of appropriate care for patients. The patient's parents gradually learned to apply parenting strategies that were not widely known by the patient's parents before. From the results, it was found that the patient's parents were better able to manage the patient in a more directed manner than before.

The patient's mother in the above case admitted that she was experiencing stress until she had time to go to a psychiatrist. Besides mothers experiencing stress in dealing with patients' daily behavior, she also claimed there was no positive support from large families. Parents of ASD children experience higher levels of stress when compared to parents of other children the same age or with other developmental disabilities. Their ability to cope with higher levels of stress depends on factors such as their own personal characteristics, child characteristics, family and social support systems, socioeconomic status and availability of professional help [4]. Another study stated that several factors were found to be associated with parental stress including social support including professional support, the severity of ASD symptoms, financial difficulties, parents' perceptions and understanding of ASD, parents' anxiety and concerns about their child's future, and religious beliefs [11]. ASD child behavior problems are strong predictors of parental stress and depressive symptoms in mothers of children with ASD, so the study suggests that one of the important goals in early intervention for children with ASD and their families is to reduce child behavior problems [12]. Interventions involving families, especially parents and children with ASD can have optimal results given the reciprocal relationship between parental stress and child's function. Parents can be educated about the stress-inducing domains of their child's functioning. Parent training can educate parents on ways to avoid negative feedback where parental stress can lead to negative parenting responses that can inadvertently reinforce

a child's maladaptive behavior [13]. There is a strong and predictive two-way relationship between emotional and behavioral problems in ASD children, parenting stress and parental mental health problems [14]. Providing Parent Training to the patient's parents in this case has helped parents to identify the sources of stress they have experienced so far.

In this case it was found that the existence of the Covid 19 pandemic situation made patients not come to undergo therapy routinely in service facilities as before, resulting in behavioral symptoms that had previously improved to reappear the last 1.5 months since not undergoing therapy. This maladaptive behavior can interfere with a child's response to educational interventions, lead to further isolation from peers, and increase caregiver stress due to disturbances in daily activities [15]. This becomes a vicious cycle in which the severity of the symptoms of ASD children triggers parental stress, which in turn will cause the behavioral symptoms to be heavier. Parents who experience depression result in less responsiveness of parents during play, which is associated with decreased child involvement, social interaction, social function of emotions, delayed language development and mutual attention. High levels of parenting stress and depression are associated with low expectations of treatment, leading to delays in the treatment process, low adherence, and early discontinuation of therapy. High parental stress levels can also hinder the effectiveness of interventions in ASD children.

By giving Parent Training Program to parents of patients, it can help parents manage children with ASD. So far the results obtained from this program are quite good although they have not yet reached maximum results, because it requires a long period of time according to the conditions of the child and family and is sustainable. Skilled parents who are involved in the intervention of ASD children provide ongoing opportunities for children as intermediaries to learn in a variety of different situations and environments, not limited to the therapeutic environment. The Intervention Parent Training Program is very important and useful, it is hoped that it can be an option to facilitate the limited availability of services, especially in the Covid-19 pandemic situation which requires the involvement and participation of parents in managing ASD children. Parents can implement the program without having to come to the service place in person. The deployment of appropriate interventions through parent training programs is also more cost effective, can increase family satisfaction and reduce the chance of children

being placed in care. A number of strategies including parent support, parent education, parent training, and parent mediated intervention can be taught to help improve parent and child behavior, teach new skills and techniques that will increase social involvement, language, play, and imitation skills of children, and the possibility of increasing generalize these skills to new environments. Its aim is to inform parents, teach them new skills, parenting strategies, targeting multiple functions and tailored to each child's needs, behavior problems and skill deficits [16]. In addition, it can help parents develop appropriate goals for their child based on a combination of developmental stages, family interests and therapy recommendations, and parents can learn to monitor their child's development over time [5]. In a Covid-19 pandemic situation it is necessary to consider the program format, intensity, location, duration and target of therapy.

Studies show that verbal communication improves as a result of parent mediated intervention, accompanied by a concomitant increase in untreated areas for all participants. There was also a decrease in autism symptoms and parents reported satisfaction with the ease of implementing the program and observing children's improvement [17]. For families who live in rural areas it can also help improve the social behavior and communication skills of ASD children [18]. This shows that parent training can overcome the problem of limited access to health services and become an effective alternative intervention for children with ASD. This can also be used by parents in the situation of the Covid-19 pandemic, which shows the state of limited access to services due to social restrictions. Greater effectiveness is obtained from the results of interventions that target the knowledge and skills of parents.

Many teaching approaches and programs exist and differ in the mode of delivery, components of therapy and target audience. Most parenting programs address core ASD symptoms such as communication, social interactions or behavioral problems. Parents can also be taught skills related to managing their own emotions, cognition and behavior, and programs that include these components of counseling are considered beneficial for parents of ASD children. Parent Training Programs conducted in high-income countries can also be used in the context of low-income countries with positive outcomes from parent-mediated interventions [19].

Several methods have been used to train parents, who have their respective benefits and limitations and are selected according to individual needs among them [7], Demonstration and Role-Play, Video Modeling, Didactic instruction and

Active Coaching. The method that is most likely to be used in a Covid-19 pandemic situation is through Video Modeling. Video modeling is a visual teaching method in which individuals (parents) watch someone engage in a skill on a DVD or video and then practice or imitate the skill observed [15]. The benefits of video modeling are similar to role play, video modeling provides various examples of targeted skills. Video modeling provides parents with a permanent product without a trainer present and can be combined with other training methods. A study conducted an intervention in a teaching format with demonstration and role play with video modeling, and the final results showed an increase in language skills and children's behavior [15]. Video recordings are also used to assess the child's progress.

Many of the reported interventions use game sessions to implement parent-mediated strategies. Play complexity has been shown to be associated with limited and repetitive behaviors, in which parents tend to influence engagement and advance play skills [20]. The techniques used focus on social interactions with other people, develop receptive and expressive language, improve playing skills, and imitate playmates to learn new skills [5].

The format of the training can be in the form of individuals (one-on-one) or groups, or a combination of individuals and groups. The most common parent training programs are one-on-one sessions with parents and children, so they can be tailored to the child's specific needs, and coaches can work directly with individual parents. Studies show the effectiveness of a one-to-one format for training parents to use a variety of training methods, including video modeling, demonstrations and role plays [7]. Meanwhile, group-based Parent training programs can be effective in reducing behavioral problems in ASD children, are more cost effective and beneficial in terms of social support, stress reduction, provide opportunities for parents to learn from other parents and function as social support groups.

As technology advances, independent technology training programs or web-based programs are also interesting [4]. Can use telehealth to provide training to remote parents or service limitations, flexible can be accessed at any time, minimizes scheduling difficulties, can adapt to various environments, individually and selected based on parental needs. Other studies have shown that the use of telehealth, web-based modules, and DVDs has several effects in educating parents and increasing adherence to intervention delivery. Interventions that were delivered using video were

said to be more effective and accepted by parents than written information [18]. Utilization of this technology can also be used in the current Covid-19 pandemic situation. Studies show that the telehealth program results in increased parental interaction, parental satisfaction, medication adherence, a higher level of involvement, better understanding and appreciation. The disadvantage is that the trainer only observes what is happening on the screen, making it difficult to assess events that might influence behavior. In addition, trainers cannot model behaviors or procedures directly.

Some of the obstacles are caused by several factors such as low socioeconomic status, the presence of situational stressors in the family, mood disorders, anxiety and stress. Families with higher stress levels show greater results when program delivery is added to individual sessions at home, so it is important further individualization to meet the specific needs of the family, for example by using video feedback for parents who have difficulty obtaining the technique directly. The cultural background of the family must also be considered for an intervention to be successful. In this case, it was found that there were several factors that became obstacles, an individualistic approach was also carried out in this case according to the conditions found in the patient's family.

In the current Covid-19 pandemic situation, patients cannot participate in therapy as is usually done in therapeutic service facilities. This brought back the maladaptive behavior of patients who had previously improved. The situation of the Covid-19 pandemic is not yet known for certain that it will end and has been going on for a long time, so it is hoped that a large role for parents to patients is expected. The Parent Training Program can be provided as an effort by health service providers to assist in the management or intervention of patients, using methods that consider the availability of resources that can be utilized, and are still possible in a Covid-19 pandemic situation.

## CONCLUSION

In certain situations, especially with the limitations of existing services such as in the Covid-19 pandemic situation, intervention methods are needed that are appropriate to existing conditions considering the many challenges faced in the management of ASD children, especially for parents that can have an impact on parental stress, and furthermore will affect the symptoms in the child [21]. Parents must be involved from the beginning in the management of ASD children, for the

selection of objectives and procedures to be carried out. The target of Parent Training is children and parents. Research to date shows that the Parent Training Program has a positive effect on children and their parents or families. The provision of Parent Training Program can be useful for increasing knowledge and insight about the individual child, enabling the incorporation of therapy into the child's own environment and facilitating generalization of the skills learned. It also can improve social behavior and communication skills, as well as parental knowledge and skills in managing behavior. Furthermore, it can reduce parental stress, improve parental confidence and quality of life, and overall improve parental psychological well-being. In this case, giving the Parent Training Program can assess the needs of the child and the family and offer support according to the needs of the family. Parents are also involved as active participants of any intervention program. Parents have unique knowledge and experiences about their own child, so they can help and support according to patient needs. This program provides quite good and meaningful results, especially in a pandemic situation. Parental involvement should be part of the intervention program and so far it has been shown to be of benefit to patients and their families. Future research needs to consider the role of fathers or mothers because each involvement involves different interaction styles and levels and sources of stress. In addition, culture and family background also play a role in family interactions with each other, in dealing with children, determining targets, and seeing the role of parents in interventions. In the Parent Training Program, health service providers must also consider family factors, address and support the needs of the entire family, not just the affected children, so as to improve the welfare and quality of life of the family in the face of an ASD diagnosis.

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