

Intervention Effort for Individuals with Autism during the COVID-19 Pandemic

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Abstract

Children with autism need interventions to deal with communication, social interaction, and behavior problems. The COVID-19 pandemic has prevented children with autism from performing face-to-face interventions outside the home. This study aims to describe the impact of the COVID-19 pandemic on individuals with autism and to describe the intervention efforts of individuals with autism during the COVID-19 outbreak. This study uses a systematic literature review consisting of three main phases, planning the review, conducting the review, and reporting the review, by analyzing 19 articles. The results show that the impact of the COVID-19 pandemic on children with autism is increased stress and anxiety. The cause of this anxiety stress is extreme routine changes that are difficult for children with autism to experience. Some of the symptoms of behavioral changes as a result of this stress include anxiety, sleep disturbances, irritability, obsessions, impulsivity. Adolescents with autism are also prone to depression. Therefore, intervention efforts that can be done are through telehealth (online health consultations and interventions), online learning, and family-based interventions with a variety of activities.

Keywords: Impact, Intervention, Autism, COVID-19

1. Research Background

COVID-19 has become a pandemic. Between February and April 2020, governments around the world announced restrictive measures to prevent its wider spread. The spread of the COVID-19 virus in Indonesia was first discovered on March 2, 2020, and this was conveyed directly by President Joko Widodo (Nuraini, 2020). The government has made various efforts to break the chain of the spread of this virus, including by issuing PP No. 21 of 2020 concerning Large-Scale Social Restrictions in the Context of Accelerating the Handling of COVID-19 which resulted in restrictions on various activities, including schools. Staying at home for parents and children is one of these steps. The impact of the COVID-19 pandemic is felt at various levels of society, including those with special needs such as children with autism.

Autism is a neurodevelopmental disorder characterized when deficiencies in social communication are accompanied by repetitive, exaggerated, and limited interests and routine and rigid behavior toward change (American Psychiatric Association, 2013). Children with autism have limitations in communication. It is characterized by a lack of reciprocity in communication, a lack of understanding of nonverbal communication in social interactions, and a lack of ability to initiate, develop, maintain and understand a relationship (Hart Barnett, 2018)). In behavior, students with autism spectrum have behavioral patterns, limited interests and activities as well as repetitive behavior. Children with autism also have challenging behavior characters such as tantrums, self-injury and aggressiveness. (Koegel et al., 2012). The sensory processing characteristics of children with autism spectrum also differ from one child to another. Sensory symptoms are a complex series of behavioral reactions to the sensory environment. Sensory symptoms can be broken down into three patterns: hyperresponsiveness (overreaction), hyporesponsiveness (underreaction), and seeking sensory stimuli (Boyd et al., 2010). Therefore, handling students with autism spectrum requires individual early intervention.

Interventions carried out as early as possible give more satisfaction to parents of children with autism than those who are detected and given intervention late. (Bejarano-Martín et al., 2020). Early intervention carried out individually supports children in developing communication and social interaction. Early intervention is also used in improving the behavior of children with the autism spectrum. The earlier the intervention is carried out, the results obtained are also faster and better for the long term.

The impact of the COVID-19 outbreak on children with autism needs to be taken seriously considering that people with autism are a vulnerable group and can affect the fulfillment of their intervention needs. The suspension of face-to-face education, extracurricular activities, social activities, and routine health care threatens the physical and mental well-being of children. Families around the world are faced with the question of how best to support their children in these conditions. The pandemic is even more disturbing for those with special health needs. Children with autism are particularly vulnerable to the negative consequences of the COVID-19 pandemic. The COVID-19 pandemic has disproportionately affected people with special needs, including children with autism (den Houting, 2020). Autistic children aged 18 to 24 months should still require medical care and ASD screening should also be postponed or canceled. Meanwhile, delayed treatment of children with autism has been shown to worsen behavioral and cognitive outcomes (Zwaigenbaum et al., 2015). In addition, autism often co-occurs with physical disabilities, including epilepsy and cerebral palsy, which can increase the risk of severe complications from COVID-19. In addition, this comorbid worsens the development and behavior of autistic children if not handled optimally.

In this situation, managing a child with autism is a challenge for families and caregivers. Parenting children with autism spectrum disorders causes more stress for parents than children with special needs in other types (Dabrowska & Pisula, 2010). Based on a study conducted by Schieve et al. (2007), parents of autistic children can experience

high stress and irritation with the behavior of their autistic children. Usually, children follow the intervention for several hours a week at home with special therapists or in special hospitals and institutions. However, at this time due to social restrictions to prevent the transmission of COVID-19, both families and children with autism are not physically supported by therapists, and they are unable to follow outside interventions.

Children with autism thrive most when they are in a caring and supportive environment that gently challenges their social development (often through school, play with friends, and therapy). As such, the nature of social isolation during the COVID-19 pandemic makes this almost impossible to do with anyone other than close family members. Children with ASD also do best when daily routines are predictable (Hyman et al., 2020). However, COVID-19 has removed all that predictability. Individuals with autism end up communicating their distress with the uncertainty of the pandemic through aggression, tantrums, or refusal to engage in daily activities. While physical activity can have a calming and regulating effect, they don't have access to indoor or outdoor spaces for that activity. In addition, picky eating can be an existing challenge for individuals with autism that can be exacerbated by the unavailability of their favorite foods in restaurants or the grocery store. In addition, the mandatory use of masks is disturbing for any child who has sensory sensitivity and may not understand why.

Based on these conditions, this literature review study aims to describe the impact of the COVID-19 pandemic on individuals with autism. This study is also to explore the intervention efforts of individuals with autism to intervene during school closures in the COVID-19 outbreak. So that, later it can be used as a guide for parents in providing interventions to children with autism as much as possible. Families, especially parents, have an important role in providing interventions for autistic children during the COVID-19 pandemic.

2. Research Methodology

The literature review study method is used in solving the problems in this study. A systematic literature review often abbreviated as SLR or in Indonesian called systematic literature review is a literature review method that identifies, assesses, and interprets all findings on a research topic, to answer research questions that have been determined previously (Kitchenham & Charters, in Wahono 2016). Furthermore, Kitchenham (2007) describes the stages of conducting a literature review which consists of planning a review, conducting a review, and reporting a review.

The first step is to plan the review (Planning the review). In planning a review, what is done is the reason why you choose the topic to be discussed, and what is the urgency of the topic being discussed. In addition, this plan will discuss the purpose of the literature review that will be carried out. Then, determine research questions consisting of, (1) the impact of the COVID-19 pandemic on individuals with autism, (2) intervention efforts of individuals with autism during the COVID-19 pandemic. After identifying what questions

are important to support this research, then develop a review protocol. A review protocol is a set of rules that outlines the content of research carried out in a predetermined format.

The next step is to do a review (Conducting the review). This study uses the results of relevant research. After that, the researcher assesses the quality of the study according to the review protocol. Data collection was carried out by selecting and collecting data related to intervention efforts against autism during the COVID-19 pandemic. The selected data must be able to be used to answer research questions. Seventeen articles related to interventions for individuals with autism have been selected through several works of literature such as articles and journals found on Google Scholar. The keywords used are intervention, autism (which allows tracing for autism, autism, autism), and COVID-19 in English and Indonesian. The articles you are looking for are articles published within the past 2 years or around 2020 to 2021, or when the COVID-19 pandemic appears. The types of research conducted by these studies are quantitative and qualitative. The study was conducted by recording information about the author, and the findings or conclusions of the study. Then, the data were analyzed by synthesizing the research findings. The next step is to extract and monitor data by entering data into the database so that it can be synthesized and concluded. At this stage, the author reviews the literature review in detail and in-depth to get the findings/core importance. So that the important points from several research results, the results of the sources are extracted and packaged into topics of discussion that are denser and do not contain bias. After that, the last step is for researchers to report the results of the review (Reporting the review) by presenting the research results in the form of scientific articles. In this stage, the researcher writes the research results in the report document. Then the final process of this literature review is to draw conclusions based on data analysis.

3. Result

3.1 Impact of the COVID-19 Pandemic on Individuals with Autism

Individuals with ASD may be more vulnerable in this pandemic because of the communication, socialization, and executive function differences inherent in diagnosis (American Psychiatric Association [APA], 2013) and common coexisting conditions (eg, anxiety disorder, intellectual disability). This will certainly have an impact on children with autism. COVID-19 has an impact on children with autism, namely increased stress and anxiety. (Kalvin et al., 2021; Amorim et al., 2020). According to Amorim et al., (2020) the psychological impact is felt by children with autism and their families. His study showed that autistic children and their families experienced stress and anxiety during the quarantine period (Amorim et al., 2020; Alhuzimi, 2021; Althiabi, 2021; Levante et al., 2021). They experience a behavior change. Some of the symptoms of this behavior change include anxiety, irritability, obsession, impulsivity. In addition, emotional disorders are also experienced by children with autism, especially those who have maladaptive characters. The main cause of stressor in children with autism according to Amorim et al.

(2020) is a change from routine. The demands of school and social involvement that children have been doing every day must stop so that children with autism experience higher anxiety. This causes children with autism to be inflexible and become a risk group for mental health complications from COVID-19. Children with autism communicate their anxiety by being angry, aggressive, and refusing to carry out daily activities (Bellomo et al., 2020).

Symptoms of stress and depression in children with autism make autistic children also experience sleep disorders (Bruni et al., 2020, Garcia et al., 2021). During the lockdown, children with autism experienced a significant increase in sleep disturbances compared to before (Bruni et al., 2020). Sleep disorders experienced by individuals with autism include difficulty sleeping, sleep anxiety, sleep terrors, and daytime sleepiness. These symptoms reflect conditions of psychological distress associated with extreme changes in the routines of children and adolescents with autism. This can affect daytime functioning or the daily activities of children with autism. However, in contrast, Garcia et al. (2021) explained that there was an increase in sleep duration in neurotypical children including autism. However, there is still speculation as to why there is an increase in sleep duration, for example, because online learning provides additional time for sleep. And bedtimes may have shifted due to the pandemic, with children going to bed later at night and waking up during the day. In this case, Garcia et al. (2021) require further research because the sample used is small. The COVID-19 outbreak has significantly exacerbated sleep disturbances in children with autism.

In addition to sleep disorders, COVID-19 has an impact on the health behavior of adolescents with autism (Garcia et al., 2021). The physical activity of adolescents with autism is impaired. Those who usually walk, run, swim, cycle immediately reduce their physical activity due to the COVID-19 pandemic. This reduction in physical activity is due to not being able to attend physical activity programs at school and fear of exercising outdoors. Instead, physical activities should be replaced by online activities and learning. Nearly all of us, as a result of restrictions on work, school, and community access experience an increase in unstructured time at home. Garcia et al. (2020) added in their research that in the end the screen time or the time or duration of children staring at the screen is increasing. This is due to boredom, and the lack of other options is the main reason for the increased screen time. The screen time in question is the time the child looks at the good layer, the smartphone or laptop layer. Screen time can be in the form of playing, communicating online, or going to school.

Schools provide opportunities for autistic children to get academic services and interventions. Adolescents with autism make school a place to be able to interact socially. However, physical distancing makes autistic children more at risk of experiencing mental health disorders such as depression (Ameis et al., 2020). Online learning is difficult for children with autism to do. The use of online platforms for the education of children with autism will be difficult because of the communication and cognitive barriers they experience. In addition, online schooling also depends on the access and availability of

digital access at the child's home. Pandemic will be a challenge in the education of autistic children, thus burdening parents' socio-economically.

The shift from education to distance learning makes parenting a child with autism more challenging. (Baweja et al., 2021; Parenteau et al., 2020) Children will always need their parents to operate laptops and tablets. The interaction that autistic children build with their virtual teacher will not be optimal and will not be conveyed properly. Children with autism need direct instruction in communicating. In addition, visual support is needed for children with autism in the learning process. Adapting to these circumstances requires considerable time and effort. Although parents are aware of their children's shortcomings and needs, parents may not have the training or experience to effectively implement their child's education plan. This is according to Baweja et al. (2020) also requires parents and caregivers to study, modify and adapt educational programs for their children. Furthermore, parents must also provide effective reinforcement, realistic strategies, and a continuous schedule to teach their children to do tough tasks. Children and adults with autism who struggle to maintain attention on tasks will rely on family, caregivers, or others to help them fill their unstructured home time.

Families, despite some of the difficulties that arise, have more time to spend qualitatively with their children teaching new skills such as self-reliance or self-development. (Mumbardó-Adam et al., 2021) Families are also developing new strategies for managing quarantine, such as scheduling a child with autism, using visual or new support, learning technology to learn and relax. Families will be more meaningful if they contact each other online with relatives, and receive online psychological support.

The impact of COVID-19 on individuals with autism affects the lack of specialized services for children with autism. Baweja et al. (2020) highlighted that the health care needs of children with autism are significantly unmet. Furthermore, many individuals with autism experience barriers to the services that they previously performed regularly. Some of the obstacles they experience are staff turnover and downsizing, closure of service-related communities, and significantly reducing or changing required access to specialized services (Eshraghi et al., 2020). In addition, there are special types of services or therapies that require children to meet face-to-face and at close range. For example, ABA therapy must be done face-to-face because there is behavioral observation and requires family support. Converting these services to remote services can be a new challenge. Some special services for children with autism disorders have been transferred to telehealth or remote medical services. (Eshragi et al, 2020)

Adults with autism have also experienced significant changes during the pandemic. They feel the loss of community services and the potential to lose their jobs. (Eshragi et al, 2020). Adults with autism are faced with major problems such as time being suddenly unstructured, having little support, and having difficulty adapting to rapid change. According to the hypothesis of Baweja et al. (2020) adults with autism are experiencing significant economic hardship due to the pandemic. As countries begin to "re-open" after

the pandemic, the return of community activities such as school and work will pose challenges for individuals with autism. The social environment will also be anxious for autistic individuals. Unpredictable changes cause anxiety for individuals with autism, for example by wearing masks and physical distancing. It will be stressful when they have changed something for a long time then return to the activities they used to do.

3.2 Intervention Efforts for Individuals with Autism during the COVID-19 Pandemic

Individuals with autism need special services that can address their social and behavioral communication barriers. This article analyzes 19 studies of individual intervention efforts with autism. In summary, the literature is presented in the following table:

Table 1. Interventions for Individuals with Autism during the COVID-19 Pandemic

No.	Research	Types of Research	Intervention	Results
1.	Mumbardó-Adam et al., 2021	Quantitative with In-depth approach	Family management and external support	more communicative, participate more often in family routines, and in making decisions about family activities.
2.	Cahapay, 2020	Qualitative	Home education, online intervention	There should be more interventions carried out at home. The more interventions, the better
3.	Daulay, 2021	Phenomenological approach	Home education	Less than optimal
4.	Ellison et al., 2021	Systematic Review process	Early intervention, applied behavior analysis (aba), functional communication training, and parent training by telehealth intervention	the use of telehealth, especially video conferencing and training is feasible and satisfying to provide various interventions to children and adolescents with autism

5.	Narzisi, 2020	Research and Development	Interventions through telemedicine	Telemedicine should not completely replace face-to-face clinical services; however, at this point, it may be necessary.
6.	Kalvin et al., 2021	Literature review	Cognitive-behavioral therapy (CBT) via telehealth	via telehealth may present beneficial opportunities and for the unforeseen tailored care to better
7.	Majoko & Dudu, 2020	Qualitative	Home education	Not explained
8.	Park et al., 2020	Quantitative single-subject design	A family-centered early intervention program	social interaction skills of all participants increase, the quality of social interaction increases M-CHAT-R/F scores decreased significantly in participants with autism
9.	White et al., 2021	Survey	Intervention via telehealth	Not explained
10.	Yarımkaya & Esentürk, 2020	Literature review	Home-based exercises (physical activity)	Not explained
11.	Morales et al., 2021	Quantitative	Judo intervention	Positively influences repetitive behavior, social interaction, social communication, and emotional response
12.	Nohelty et al., 2021	Quantitative	Telehealth direct therapy (ABA via telehealth)	Effective and can be considered in the treatment of children with autism

13.	Sergi et al., 2021	Quantitative	Applied behavioral analysis interventions	Skills remained, but no significant improvement was demonstrated.
14.	Stenhoff et al., 2020	Literature review	School-based instruction	
15.	Su et al., 2021	Literature review	Telehealth interventions	Not explained
16.	Khaelani, 2021	Literature review	Online learning through Whatsapp media	Not explained
17.	Fadhilah, 2021	Literature review	Online learning via Whatsapp Video Call Application	communication skills of children with autism can be improved by utilizing the video call feature on the Whatsapp application
18.	Laili, 2021	Literature review	Yoga by parents	Boost the immunity, improve physical fitness, improve motor skills
19.	Yuwono, 2020	Qualitative	Online by direct/face-to-face (video conference) and assigning tasks to parents of autistic children.	Not effective

From what has been explained, the services that can be used by children with autism during COVID-19 are:

1. Online learning and Telehealth (Online Health Consultation and Intervention)

There are many benefits of telehealth apart from increased convenience. Disruption of face-to-face services causes delays in diagnosis for many people, resulting in delayed access to treatment. Diagnostic assessment of autism via telehealth was minimally researched before the pandemic (Juárez et al., 2020).

Telehealth has become an important resource for many, as the availability and capacity of healthcare providers and systems have been severely limited for in-person care delivery during this pandemic. However, telehealth continues to have some limitations including reliance on technology, which may be unreliable, especially during high usage times as is often seen during

pandemics. Telehealth may also be difficult to access for patients who may be socio-economically or techno-geographically disadvantaged (Baweja et al., 2020). Telehealth has been well received by adolescents with ASD and their parents. Despite these barriers, telehealth remains a viable alternative for individuals with ASD when face-to-face encounters are impossible or impossible. Remote services have the potential for individuals with ASD to provide a range of services such as individual therapy, family consultation, skills transfer and skills maintenance, and addressing behavioral difficulties and communication needs. In the field of education, telehealth can also be said as online distance learning or online. Several types of online interventions are ABA and CBT.

2. Family-based interventions (Home intervention)

If children with autism require intervention services and cannot travel due to social restrictions, parents can provide interventions themselves at home. This is also known as home intervention or home education. Family-based interventions carried out at home can be done by training children's independence. (Daulay, 2020, Mumbardó-Adam et al., 2021). In addition, (Daulay, 2021) also teaches simple academics to children because previously he did not include his children in therapy programs. In addition to being given independent and academic training, children with autism can be given physical exercise. Families have a great responsibility for children with autism to have a healthy time in isolation days. (Yarımkaaya & Esentürk, 2020). Parents can access many articles that provide examples of physical activity for children with autism during the COVID-19 outbreak, so parents have a choice of physical activity strategies for their children. Interventions through physical activity can use games, exercises, yoga, and sports carried out by parents with their children. The purpose of physical activity can be to strengthen muscles, have fun, reduce anxiety, increase attention and decision making, gain flexibility, strengthen breathing in children with autism (Yarımkaaya & Esentürk, 2020). Some forms of physical activity that can be done are 1) taking online exercise classes, 2) meditation, 3) stretching and cooling down, 4) educational games, 5) functional exercises, 6) going up and downstairs, sit-ups and push-ups, 7) walking -walking at home, 8) namesake aerobics, fitness, cardio activities, 9) home-based exercises, 10) rest during the day, 11) LEGO therapy, 12) warm-up movements (Yarımkaaya & Esentürk, 2020).

Narzisi, 2020a provides 10 tips to help parents and caregivers to deal with children with autism disorders during the COVID-19 pandemic at home. These tips are as follows:

1. Explain to your child what COVID-19 is

Children with autism have concrete learning styles and some of them can have serious verbal problems resulting in difficulties in phenomenological

perception. It is important to explain what COVID-19 is and why we should all stay at home. This can ask the therapist for help in preparing a short pamphlet entitled 'What is COVID-19?' For verbal children, the explanation must be supported by concept mapping and visual support to make it easier for children to understand.

2. Structure the Activities of Daily Living

Children with autism have executive function deficits [and they may show problems planning their activities of daily living, especially when their routines are disrupted. For this reason, it is important, especially now, to structure the activities of daily life. Arrangements can be by dividing daily activities, different rooms for different tasks. This structure can be useful not only for low-functioning and/or intermediate-functioning children with autism but also for those with high functioning.

3. Handle Semi-Structured Play Activities

Children with autism enjoy playing, but they may find some types of play difficult because of sensory problems or because they prefer structured or semi-structured activities. During the day, it is important to engage in play activities. Choose an activity that your child enjoys. For example, LEGO therapy can be a great option. LEGO-based therapy is an increasingly popular social skills program for children and adolescents with social communication problems such as ASC. It can be a semi-structured play activity that is shared with parents or siblings in the home environment.

4. Serious Game Use

Serious play can be useful for improving social skills and for recognizing facial emotions, emotional movements, and emotional situations in children with autism. Many serious games are free and can be downloaded as apps for tablets and/or PCs from specialized sites.

5. Sharing Video Games and/or Internet Sessions with Parents

Video games and the internet are of great interest to children with autism but they can be an absorbent interest, especially at this period when children are called upon to stay home. It is impossible to avoid children playing with computers but at this time, when parents are also at home, it can be useful to establish rules by which children are restricted in playing games. This can avoid the potential risk of child isolation and internet addiction.

6. Applying and Sharing Special Interests with Parents

Special interests can be a hallmark of children with autism. Children's special interests must receive support from parents and/or caregivers. Trains, maps, animals, comic books, geography, electronics, and history are just a few of the

potential special interests a child has. At this time when parents and children stay at home, they can plan some activities by sharing this special interest.

7. Online Therapy for High Functioning Autism Children

It is well recognized that psychiatric susceptibility and/or comorbidity are high in children with ASC. Among these comorbidities, anxiety disorder is one of the most widely reported. If children were involved in psychotherapy before COVID-19, then they can continue their therapy. This is to reduce anxiety, calm the mood, and offer children a private space to talk to a specialist.

8. Weekly Online Consultation for Parents and Careers

Parents of children with autism experience more stress and are more vulnerable than parents of other children with disabilities. Nowadays, when parents are alone in dealing with their children with ASD, they can be at further increased risk for their stress levels. Therefore, it can be very useful to have the opportunity for weekly online consultations with her child's therapist. This applies to parents of both low and high-functioning children.

9. Maintaining Contact with School

A growing body of research supports the suggestion that the relationships children form with their teachers and classmates have a positive impact on learning. For social maintenance, contact with schoolmates is recommended to have at least weekly contact with one of the classmates. This contact should depend on the child's preferences regarding what media to use and who to contact. For children and parents, it is also highly recommended to maintain contact with specialized teachers online or by phone.

10. Leave Free Time

Children with ASD should be stimulated, as indicated in tips 1–9, but it is possible to give them free time.

4. Conclusions and Suggestion

The COVID-19 pandemic has had a major impact on children with autism. The perceived impacts include stress and anxiety. Interventions are still needed to manage communication, social interaction, and behavior. Interventions are increasingly needed to deal with psychological problems experienced by children with autism. However, the COVID-19 pandemic has forced parents and schools to have appropriate intervention efforts for children with autism because of regulations for physical distancing. Based on research, telehealth or online learning, and family-based interventions are intervention efforts that can be done during the COVID-19 pandemic. Therefore, teachers are advised to try to do well in learning and find the right method for online intervention for autistic children. Teachers can also provide intervention materials that can be done easily with parents at home. Suggestions for parents are to always be involved in interventions and

provide interventions that have been prepared by teachers and parents to reduce children's stress and anxiety levels and can handle barriers to children with autism. In addition, interventions given to children will improve their communication, social and behavioral skills.

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