

Journal of Educational Studies and Multidisciplinary Approaches (JESMA)

www.jesma.net

Psychological Impact of the COVID-19 Pandemic on Children with Disabilities and Their Families

DOAA SAMY SAEID EI SAYED¹

To cite this article:

ELsayed, E.D. (2022). psychological impact of the COVID-19 pandemic on children with disabilities and their families. *Journal of Educational Studies and Multidisciplinary Approaches (JESMA)*, 3 (2), 198-215. <https://doi.org/10.51383/jesma.2023.76>

Journal of Educational Studies and Multidisciplinary Approaches(JESMA) is an international scientific, high quality, open access, peer viewed scholarly journal that provides a comprehensive range of unique online-only journal submission services to academics, researchers, advanced doctoral students and other professionals in their field. This journal publishes original research papers, theory-based empirical papers, review papers, case studies, conference reports, book reviews, essay and relevant reports twice a year (March and September).

Psychological Impact of the COVID-19 Pandemic on Children with Disabilities and Their Families

DOAA SAMY SAEID ELSayed <https://orcid.org/0000-0002-4136-579X> 

ARTICLE INFORMATION

Original Research

DOI: 10.51383/jesma.2023.76
Received 15 December 2022
Accepted 26 September 2023

ABSTRACT

The current study aims to reveal the impact of the COVID-19 pandemic on children with autism spectrum disorder (ASD) in Egypt. It also focuses on the perceptions of their parents and the difficulties they faced during the pandemic. The study focused on collecting data from four to ten-year-old autistic children and their families, who frequently attended a day-care center in Cairo, Egypt. qualitative ethnographic method design was used in the study, with qualitative data collected from 20 families using semi-structured interviews. The Adaptive Behavior Scale (ABAS-11) was applied and analyzed using content analysis. The findings showed the pandemic had a negative impact on the psychological and behavioral aspects of children with ASD, as well as a negative psychological impact on their families. It calls for the continued need for parents and their children for counseling, guidance, and psychological support. This negative impact on families was because of the parents' lack of knowledge of the characteristics of their child with a disability. The study concluded that it is necessary to train parents on how to deal well with their children with disabilities, an outcome of this study, the researcher launched an initiative called 'The Specialized Mother Initiative' and has invited over 50 Egyptian institutions working with children with disabilities in over 15 governorates. Its aim is to train Egyptian families on the scientific method of dealing with their children with disabilities, and in particular, children with autism.

Keywords: Corona pandemic, Children with Autism Spectrum Disorder (ASD), psychological impact



This is an open access article distributed under the terms of the [Creative Commons Attribution License](https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution and reproduction in any medium, provided the original authors and source are credited.

Introduction

To prevent the outbreak of Covid-19, governments all over the world, including Egypt, have taken precautionary measures. These include the closure of public and private schools and centers and imposed curfews. These measures had a significant impact on children with ASD and their families. These children may quickly lose skills they have formed in the past. Therefore, it is likely that the precautionary measures put in place to prevent the outbreak of COVID have led to a relapse and increased the severity of the primary disorder symptoms, especially from the behavioral side, because of not being able to continue training and education. As families depend on specialists and teachers in schools and centers, the inherent characteristics of children with ASD, represented by deficits in communication and social interaction and restricted behavioral patterns, interests, and activities, make these children face difficulties because of changes in routine and environment related to the measures taken due to the pandemic, and an increase in stereotyped behaviors, opposition, and aggressive behavior toward self, objects, and others.

The COVID-19 pandemic has changed how the local and global communities operate, these measures influenced the mental health and well-being of individuals with autism and their families. Individuals with ASD have high rates of combined physical and mental health conditions (e.g., digestive and sleeping problems, ADHD, anxiety, and depression) throughout their entire lives (Lai et al., 2019).

Studies have shown that the COVID-19 pandemic has a severe impact on the psychology and behavior of children with ASD. Negative behaviors have increased because of changing daily routines. These children also experienced an increase in the levels of anxiety and stereotypical movements, sleep disorders, and lack of social interaction. Families had a hard time as they could not have a break by sending their children to day-care centers (Eshraghi et al., 2020).

Therefore, this study aims to answer a set of important research questions:

- What happens when families spend the entire day with their autistic children?
- How does contribute to increasing their behavioral and communication problems?

Therefore, this research attempted to describe the negative effects that occurred on children with ASD during home isolation, and the psychological effects that followed the entire family from staying home for a child with ASD for a long time without rehabilitation. This paper explores the possible reasons for this negative impact on families, and ways to solve this, if the world is swept by new disasters that would disrupt daily life.

Impact of lockdown on children with ASD and their families

The Centers for Disease Control and Prevention (CDC, 2021) have classified people with ASD as those most at risk of developing COVID-19. Moreover, autistic people are at high risk because they have difficulty accessing information about the pandemic, understanding precautionary measures, or reporting symptoms. Autistic people also face other challenges; including problems in social communication, ADHD, and other problems that pose additional challenges to dealing with those cases during the COVID-19 (Eshraghi et al., 2020).

The vital need for similarities and adherence to routine are fundamental features for autism. These features have been linked to high rates of anxiety and depression experienced by individuals with autism (Baribeau et al., 2020). Changes in daily routines and restrictions on regular service disrupt several areas (e.g., physical, and mental health, and other family factors). Limited access to specific types of goodies may affect autistic individuals who suffer from eating disorders (Curtin et al., 2015); leading to reduced food intake, malnutrition, or digestive and constipation problems. Furthermore, restricted access to programs, activities, and preferred places contributes to reduced physical activity, a concern among individuals with autism, and high obesity rates (Must et al., 2017).

Given that the mother cannot deal and intervene with her child with autism spectrum disorder ASD well and that the child with ASD has one of his special characteristics that refuses to change the routine, and is locked in the house all the time, this matter became difficult for the child. As a result, behavioral problems, such as screaming and crying, increased significantly. In addition, eating and sleep schedule disorders have been reported. Some children reported sleeping for a very long time, and others did not sleep for a long time that reached 24 hours. With regard to eating disorders, some children refused some of the available types of food, and this constituted a great difficulty for families. The need to provide their child's favorite foods was problematic as due to shops' closure during lockdown. These difficulties that the child suffered from constituted difficulties for the entire family. Mothers would try calming the child down and please him. When it was difficult for her, she resorted to screens, whether television or mobile, in an attempt to overcome the behavioral problems that appeared strongly, such as aggression against himself or those around him by severe beatings and breaking household items and others. To avoid this, the child spent long periods in front of screens in order to entertain and distract him. This in itself has greatly negatively affected child's cognitive skills. This was also found in other literature (Slobodin et al., 2019; Schreck & Rochdale, 2020; Fitzgerald et al., 2016).

Asbury et al., (2021) indicated that to obtain a better understanding of the needs of children with ASD and their families, there is a need to identify factors that make compatibility easier (facilitators) and those that hinder compatibility (barriers) during the pandemic. This may result in recommendations that could help guide services by recognizing the perceptions of those children and their parents.

Colizzi et al., (2020) conducted a study to verify the negative impact of the Coronavirus outbreak on children with ASD and their families using an online survey directed at parents. The study also aimed to confirm whether there were any sociodemographic or clinical factors prior to the pandemic that would predict the negative impact of the pandemic on the well-being of people with an ASD and identify the needs of children with ASD and their families, by gathering parents' perceptions using open-ended questions as an initial step to improve the quality of healthcare services. 93.9% of the families reported that the outbreak of COVID-19 had a negative impact on their lives and their ability to manage daily-life activities, especially during leisure time (78.1%) and organized activities (75.7%). 19.1% of parents also reported that caring for their autistic children was one of the factors that increased their mental stress during the pandemic and, therefore, they needed to receive support from psychiatrists. As parents started to notice that their autistic children were having new behavioral problems, and due to the sudden curfew, 47.4% of the participants said they needed more health services during the pandemic, 30% needed more support at home, and 16.8% needed more support from the state during quarantine.

Moreover, a study by Jacques et al., (2022) explored the impact of the Coronavirus on children with special educational needs and disabilities, and their families. 241 families from the United Kingdom were involved in the study and were asked to answer a questionnaire about the impact of the Coronavirus on their health and their children's mental health. The study showed that both children and their families suffered from loss, anxiety, and behavioral and mood changes because of social changes due to the Coronavirus. Some families also reported feeling pressured and overwhelmed, which influenced the child's understanding and awareness.

Given the nature and characteristics of these children who suffer from behavioral problems, some may refuse to use sanitizers because of their smell or sticky texture. Moreover, some patients need sensory stimulation by placing objects in their mouths, which may increase the chances of developing Coronavirus (Hill, Zuckerman, Hagen, Kriz, Duvall, Van Santen, & Fombonne, (2014). According to a study focused on the Mental Health of Parents of Children with ASD during COVID-19 Pandemic, 94% of families with children with ASD had increased stress levels during the pandemic (Yılmaz, Azak, & Şahin, 2021).

However, the impact of changes on the routine may be mitigated by creating and jointly following alternative routines, integrating regular bedtime and morning schedules, paying attention to sensory

stimulation, giving adequate but limited exposure to the media, controlling time spent on the screen, paying attention to hygiene, eating regular meals, and staying hydrated, exercising on daily bases, and sleeping. Maintaining social networks (even online) is critical for autistic individuals and their families (Ameis et al., 2020).

Technology to facilitate multidisciplinary coordinated care.

For children with ASD, the shift toward the usage of online platforms may have a lasting impact on caregiving. Involving parents in early intervention given to young children can have long-term positive effects (Lai et al., 2018). Moreover, low-cost and intensity intervention programs focused on training parents on how to interact with their autistic children can have a direct effect on their social behavior and communication (Nevill, Lecavalier, & Stratis, 2018). Growing evidence indicates that caregivers can be trained to provide immediate interventions through parents online, and online training can influence parents' knowledge, sincerity of intervention, social behavior, or communication skills for children (Lindgren et al., 2020). Additional support based on telemedical care for early intervention (via caregivers) and intervention targeting children, young people, and adults with autism using teleclinical trials should be developed and tested (Nicol, Piccirillo, Mulsant, & Lenze, 2020). These tools would significantly enhance access to services and support even after the COVID-19 pandemic (Cross & Hickie, 2017).

Online platforms can support the change to wards tailored service, away from a one-size-fits-all approach (Cross & Hickie, 2017). This can ensure that more autistic individuals have access to care and support personalized and graded care models. For example, developing a system for providing and monitoring support so that the most effective and least resource-intensive care is provided first. Some caregivers cannot access remote care while reconciling their additional workload during the pandemic. As we develop online care to improve peoples' access to it, we must bear in mind that it can lead to inequality in giving autistic individuals access to the needed care (Racine, McArthur, Cooke, Eirich, & Madigan, 2021).

Thus, to minimize the effects of the epidemic on individuals with autism at risk, complex physical and mental health care are required, including psychosocial and behavioral support for both the individual (Hill, Zuckerman, Hagen, Kriz, Duvall, Van Santen, & Fombonne, 2014). and their caregivers, who are also expected to experience high levels of stress and anxiety (Keenan et al., 2016). Data collected from 8000 parents and 600 autistic adults, using surveys, between March and April 2020 revealed that despite the severe tension, they were able to share their positive experiences adjusting to the pandemic; these included positive use of time, additional family quality time to practice hobbies, reduced access to social media and news, and exploration of activities that support relaxation. Once the restrictions placed by the pandemic are over, new models of care can be sustained and shared instead of returning to what people were familiar with and used to before the pandemic. The pandemic is an opportunity to vaccinate against stress (Lai, & Szatmari, 2019). Learning from COVID-19 means that people are well prepared for other crises in the future.

Therefore, for the Egyptian family and its child with disabilities in general, and the child with ASD, in particular, not to be exposed, it was necessary to follow two important and irreplaceable paths. The first way for them is the steer special education away from the narrow tunnel in which it runs and is limited to traditional sessions, and traditional methods of diagnosis, rehabilitation, and training, to a space of where the methods of technology and applications of artificial intelligence are beneficial. This could allow access to many applications and platforms, which would facilitate work for specialists. Secondly, involve the family in working with the child and consider the family as one of the most important members of the child's rehabilitation. This will lead them to understand the child, his needs and aspects of developmental delay, and ways to deal well with the child according to its individual needs, and this will benefit the family as well as the child.

Methods and Materials

The qualitative descriptive approach was used, which required a description of the phenomenon, and its suitability to the nature of the current research, as it aims to describe the psychological impact of the Corona pandemic on children with disabilities (autism) as a model, and on their families, during home isolation.

Search tools:

1. Stanford Bennett Intelligence Scale, fifth edition, modified by Mahmoud Abu El-Nil.
2. The Gilliam scale, third edition, for estimating the degree of ASD Translated by Adel Abdallah, Abeer Abo Elmaged.
3. The Adaptive Behavior Scale (ABS), seventh edition, translated by Dr. Safwat Farag, Dr. Nahed Ramzy.

The current research presents a summary of all study tools:

1. Stanford Interface Intelligence Test (fifth edition) (prepared and modified to an Egyptian context by Mahmoud Abu El-Nil, 2011)

A- The purpose of the scale:

It is an individual measurement to assess intelligence and cognitive abilities for an age spanning from (2-90) years. The scale is used to diagnose disabilities of all ages, learning difficulties, and progressive cognitive delay in young children, in addition to enrolling students in mentally gifted programs in schools.

B- Description of the scale:

The fifth edition consists of ten sub-tests distributed over two main areas (verbal and non-verbal) so that each field contains five sub-tests. Each sub-test consists of a group of mini tests of varying difficulty (starting from the easiest to the most difficult). Each of the mini-tests consists - in turn - of a group of (3) to (6) items or tasks of similar difficulty level, which are the items or tasks and problems in which the subject is directly tested.

The Stanford-Binet test (fifth edition) is applied individually to assess intelligence and cognitive abilities, and it is suitable for ages from (2-85) years and over. The overall scale consists of (10) sub-tests that are grouped together to form other tests, namely:

1. IQ test: It consists of two pathfinding tests, which are the Subject Strings/Matrix test and the Vocabulary test. This short scale is used with other scales or tests in conducting assessments such as the neuropsychological assessment.
2. Nonverbal intelligence test: This consists of five nonverbal subtests that are related to the five cognitive factors measured by the fifth image. Autistic disorder, some types of learning disabilities, traumatic brain injury, children with limited background in the test language and other conditions with language impairments, such as aphasia or stroke.
3. Verbal IQ test: This complements the nonverbal IQ scale and consists of the five verbal subtests related to the five cognitive factors measured in the fifth edition. The verbal IQ scale

may be fully standardized on ordinary respondents, as it is applied in some special cases. Those with poor eyesight, spinal deformities, or other problems that may prevent the nonverbal portion of the scale from being completed.

4. Total IQ of the test: It results from combining the verbal and nonverbal domains or the five factor indicators. The average time for applying the total test ranges from (45 to 75) minutes, while the application of the short task takes from (15 to 20) minutes, and the application of the domain takes about (30) Minutes each.
5. Method of grading.
 - Determine the chronological age of the examinee in year, month, and day.
 - Determining the base age of the examinee, as the examinee is left to determine the base age based on knowledge and assessment of the examinee, and the base age is defined as the age at which the examinee succeeds in all tests of that age.
 - Determining the maximum age of the examinee, where the examiner determines the top age of the examinee when he fails to answer the tests of a certain age and defines the top age as the age at which the examinee fails all the tests of that age.
 - Determining the mental age of the examinee, where the examiner determines the mental age of the examinee by adding the mental months obtained by the examinee on each of the tests that he succeeded in performing according to the standards of those tests, adding to it the base age.
 - Determine the standard score for the test, which is interpreted as follows:
90-110 average.
70—89 is below average.
55-69 Mild intellectual disability.
40-54.1 moderate intellectual disability.
25-39.1 Severe intellectual disability.

Psychometric characteristics of the test's reliability were calculated for the different sub-tests by the two methods of re-application and split half calculated by the Alpha Cronbach equation (0.870 and 0.991)

2. The Gilliam Estimated Scale for the Diagnosis of Symptoms and Severity of ASD, third edition, GARS-3. Translated by Adel Abdullah, Abeer Muhammad 2021.

The third version of the Gilliam scale is a standard reference test used as a tool for sorting and filtering, diagnosing ASD, and identifying individuals them in the age range of (3:22) years. The scale consists of (58) items distributed into six subscales.

- Restrictive or repetitive behaviors: This includes 13 items that measure stereotypical behaviors, restricted interests, routines, and rituals.
- Social Communication: It includes nine vocabulary words that measure an individual's responses to social situations and contexts, and his understanding of the content of social interaction and communication.
- Emotional responses: It consists of eight items that measure the extreme emotional responses of individuals to daily social situations.

- Cognitive style: It consists of seven items that measure the fixed strange interests of individuals, and their characteristics and cognitive abilities.
- Inappropriate Speech: It consists of seven vocabulary words that describe deficiencies in the child's speech, and oddities or abnormalities in verbal communication.

Scale application:

The items of the scale are answered by the parents, the specialist, or those who know the child well and the behaviors that he performs, by choosing one of the four options available in front of each item, namely (yes, sometimes, rarely, no), which are corrected as follows: (3, 2, 1, zero), and thus the degree on the scale ranges between (0, 174) degrees. The six scales are applied together to children who have a level of verbal communication, whereas children without verbal communication are applied to the first four subscales only, the raw score for each sub-scale is then converted into percentile ranks and indicators of autism disorder. Considering whether the scale has been applied as a whole or four scales only, through the criteria tables for the scale, a score of (45) or less indicates that there is no ASD. A score of (55-70) indicates that the child has a mild ASD, and a score of (-71) 100) indicates moderate ASD, while a score of (101) or more indicates severe ASD.

Adel Abdullah and Abeer Muhammad (2021) verified the psychometric properties of the scale on a sample of children with ASD, as the sample reached (100) children with ASD, who attended day care centers for individuals with disabilities from cities Zagazig, Famous, and Husseiniya in Sharkia Governorate, whose ages ranged between (6-12) years. The results showed that the third version of the Gilliam scale for diagnosing the symptoms and severity of ASD in its Arabic form is characterized by good psychometric characteristics that can be relied upon in diagnosing the symptoms and severity of ASD.

3. The Adaptive Behavior Scale (ABS), seventh edition, translated by Dr. Safwat Farag, Dr. Nahed Ramzy

The American Mental Disorder Association's Adaptive Behavior Scale is a rating scale for the mentally disabled, emotionally incompatible, and impaired. It can be used similarly to other individuals with other manifestations of disability. It is designed to provide an objective and evaluative description of an individual's adaptive behavior. The term "accommodative behavior" was introduced and defined by the Association. American mental disability in the first editions of its guide to terms and classifications of mental retardation and is still used in the new edition of the guide, and the expression refers mainly to the effectiveness of the individual in dealing with the natural and social demands of his society.

The Adaptive Behavior Scale consists of two parts:

The first part: It is the result of a comprehensive review of behavioral measures available in the United States and England. The scale has been subjected to many modifications because of an in-depth analysis of the items. The items of the scale were evaluated and chosen based on the reliability of the correctors or estimators, and the effectiveness of the items in distinguishing between consensual behavioral levels, if the intelligence variable was applied.

It includes the first part of the Harmonic Behavior Scale according to progressive axes (or lines) and is designed to evaluate the individual's skills and habits in ten behavioral domains (which are interconnected groups of interrelated activities) that are important for improving personal independence in daily life. Below are these ten domains, illustrated by numbers, and what they include. It comprises 21 subfields, which are described as follows:

1. Independent work: (eating, using the toilet, hygiene, appearance, taking care of clothes, dressing and undressing, moving around, general independent behavior).
2. Physical development: (sensory development, motor development).
3. Economic activity: (money handling, budget planning, purchasing skills).
4. Language improvement: (expression, understanding, social language improvement).
5. Preparation and time.
6. Household activities: (cleaning, kitchen work, and other household chores).
7. Professional activity
8. Self-orientation: (initiative, perseverance, free time).
9. Take responsibility.
10. Socialization.

The second part included measures related to personality and behavior disorders, and the fourteenth section in this part, titled “Drug Use,” is not actually a spoof field, but provides information about the person’s harmonious behavior with the outside world. This second part consists of the following fourteen areas: (destructive violence, antisocial behavior, rebellious behavior, distrustful behavior, withdrawal, stereotypical behavior, abnormal behavior, inappropriate social behavior, unacceptable vocal habits, unacceptable antics, self-harm behavior, abnormal sexual behavior, psychological disorders, drug use).

Method

During the pandemic, the entire world was exposed to the Corona virus. Similar to many other countries, in Egypt, a nationwide lockdown was imposed on all sectors of work, schools, shops, etc., including special education centers like the Itqan Learning Center. These centers were significantly affected by the pandemic, because it was necessary to stop all rehabilitation programs and prescribed diagnosis. The fact that the most vulnerable children had to stay at home during these times, resulted in the need for the author as the director of the center to follow up with the children at home during quarantine and home isolation. Due to the restrictions, this had to be done through the online platform Zoom according to a schedule and a plan established to follow up with each case. This developed into a research project aimed at identifying the impact of the lockdown on ASD children and their families. As the center, like many other institutions, was unprepared for such circumstances, a greater understanding was needed for staff and families in aid of preparation and management of any for future lockdown or other national restrictions. As such, the researcher consulted the parents who welcomed the idea and cooperation with the researcher.

All participants in this study included parents whose families were receiving therapy from the Itqan Learning Center, which is owned by the researcher. The author is a practitioner-researcher and conducts this study as an insider. All participating families live in the vicinity of Greater Cairo, at a medium social, economic, and cultural level, and have home internet, The children were aged between 4 and 10 years, had a good level of adaptive behavior, and the child's IQ score was not less than 70.

To collect qualitative data for this study on children with ASD and identify the impact of isolation on them, the most appropriate method under the circumstances was the ethnographic method. Ethnography is a qualitative method for collecting data that is often used in the social and behavioral sciences. Due to the lockdown, the data had to be collected online via Zoom and video recordings. Video ethnography is a powerful tool for the study everyday activities and observations (Chen,2021). Data was collected through observations and interviews, which are then used to draw conclusions about the family’s and individual’s function. By observing the child within the context of the family, and regularly meeting the parent online, the author was able to follow up the child and assess the extent of development or relapse of the child's skills (Howlett, 2022).

Each parent completed 20 semi-structured interviews in approximately 5 months. This enabled building trust and rapport with the researcher and feeling comfortable in opening up about the challenges the families faced during home isolation. This was performed according to an organized project plan from December 2019 to April 2020, once every week for each family. The duration of each meeting is 60 minutes. The researcher met 20 families per week to follow up on each child and his/her family, their methods of dealing with him/her, and the problems that arose during the pandemic. At the beginning of the research period, the researcher applied the adaptive behavior scale used in the study, to identify the child's level before and during isolation, and to determine the impact of isolation.

The researcher would start the meeting by greeting the family and checking their well-being. She would give the family the details of the child during the week and the problems they may have suffered from.

The researcher will also answer any of their questions. To find out about the developments that occur to the child during isolation, she recorded observations and provided instructions to them. At the end of the research application period, the researcher applied with the family for the second time on the scale to determine the difference between before and during isolation. These meetings continued throughout the research period and continued after the study to provide support and guidance to the families.

Therefore, ethical research requires adherence to the technicalities of the ethics process. Application for ethical approval, providing participants with information about the research project and providing informed consent. Both recording tools, if used, and the transcribed data, if relevant, should be stored in a safe place in an encrypted form. Additionally, and to the degree possible given the specific research project, participants should be given anonymity. This is considered by the researcher that ethics is not only considered prior to the study but as a continuous process of competence.

Sampling

The current study sample consists of 20 children with ASD who are enrolled in the day care of the Itqan Learning Center, which is owned by the researcher, the study purposive sample was chosen intentionally due to the availability of a set of criteria necessary for the application of the study, which are as follows:

1. The chronological age ranges between 4 and 10 years.
2. Intelligence is not less than 70 according to on the Stanford-Binet scale, (fifth edition with Prof. Dr. Safwat Farag's standardization).
3. Autism is not more than 70 according to the Gilliam Intelligence Scale, third edition.
4. The child has average verbal communication skills that can express his simple needs with a two-word sentence.
5. The child has an appropriate level of adaptive behaviour skills that help him socialize acceptably with guidance.
6. The child has a moderate skill in self-care.
7. Does not suffer from eating disorders.
8. Does not suffer from sleep disorder.

Because the researcher is a gatekeeper, she was very familiar with the children, in relation to their skills, abilities and development of the child's growth for years of rehabilitation and was very aware of the strengths and weaknesses of each child of the sample. All tests and assessments taken before the lockdown were carried out under her supervision, therefore, she was very familiar with all children in the sample., Out of 45 children, 28 children were identified who met the required criteria, and the researcher contacted each family of the 28 children individually to explain the research, aims and objectives and methods. It was clarified that participation in this study is completely voluntary, that

participants could withdraw at any time, and that the data will be treated with complete confidentiality anonymized and will be used only for scientific research.

Two families apologized because the area in which they live did not have fixed internet connection, and this may prevent their regularity in the application. Furthermore, 4 families suffering from unstable family conditions that may prevent them from following up well with the child were excluded, and two further families did not provide consent. Therefore, the sample was limited to 20 families who participated by providing full informed consent.

Ethical Considerations

Research should be responsibly organized and practiced, and research ethics is a tool for this purpose. Researchers and research institutions are both responsible for ensuring compliance with research ethics, and other research actors should behave in accordance with ethical norms and guidelines (NESH, 2022). It is argued that insider researchers always have a passion for the topic they have been working on (Saidin, 2016). Research ethics consists of common norms, derived from society's demands and expectations of research in a broad sense. Human dignity constitutes the core value in this context, and it is protected by three principles: respect for equality, freedom and autonomy, beneficence, protection from the risk of significant harm and unreasonable burdens, and justice in procedures and the distribution of benefits and burdens (Greaney, Sheehy, Heffernan, Murphy, Mhaolrúnaigh, Heffernan, & Brown, 2012).

As a practitioner researcher, I did not have an ethical board to seek approval from. However, as an insider and practitioner, I considered the following ethical issues to ensure trustworthiness and credibility and prioritize the best interest of the family and the child with ASD.

- Everything that will be done in the study is surrounded by a high degree of confidentiality and complete privacy between the family and the researcher.
- All the attached data are for the benefit of scientific research only and will not be publicly shared.
- In addition, the data that will be published is anonymized and does not provide information about the child and his family.
- The family has the right at any time to withdraw from the application if they wish.
- Telephone meetings, whether video or audio, are limited to the family and the researcher only, and are not recorded.

Findings

The current study concluded that after applying some dimensions of the first part of the adaptive behavior scale, only the following dimensions were applied: independent work, physical growth, economic activity, language development, preparation, and time. The researcher proves choosing only the first part without the second part of the scale, because the second part in many of its parts is not considered adaptive behavior for young children, who also suffer from ASD. Therefore, if the child is evaluated in this aspect and receives a high score, it is not considered evidence of poor adaptive behavior, because he is young, and these behaviors may appear from a young child and are considered acceptable.

The researcher argues that choosing the first five dimensions from the first part and abandoning the other four dimensions, the remaining three dimensions are the professional activity that measures the performance of the child in a job assigned to him, and because the child is young and has ASD, this dimension is not required of the child, and the second dimension is the self-orientation that Initiative, perseverance, and spending free time branch out from For the same reason, it was abandoned. The third dimension, which measures responsibility, and the fourth dimension, which measures socialization, were abandoned because they measure the child’s relationships and interaction with others, and because we are in the period of domestic isolation, it is difficult to measure this dimension. After applying the five dimensions of the first part of the scale, the researcher obtained the following results:

Table1. Children’s score on the first part of the scale

Child	independent work		physical growth		economic activity		Language elevation		preparation and time	
	before	during	before	during	before	during	before	during	before	during
1	47	26	22	13	2	0	11	2	8	3
2	44	20	20	11	1	0	10	5	8	2
3	39	18	21	12	2	0	9	2	7	2
4	48	28	19	10	2	0	8	1	6	2
5	35	21	22	11	2	0	7	3	8	2
6	45	20	23	10	2	0	12	7	7	2
7	40	15	19	10	1	0	12	9	6	1
8	39	19	18	10	2	0	7	1	8	0
9	46	22	20	12	2	0	9	5	7	0
10	41	20	21	13	2	0	10	7	7	3
11	44	19	17	12	2	0	11	8	8	2
12	35	15	21	12	1	0	9	2	8	2
13	37	21	20	11	2	0	6	1	6	1
14	41	21	22	13	2	0	10	1	7	0
15	46	23	22	13	2	0	10	3	7	3
16	39	19	21	12	2	0	12	3	7	3
18	42	20	16	11	2	0	10	2	8	2
19	46	23	17	10	2	0	8	1	8	2
20	37	17	22	11	1	0	12	3	7	2

Table 2. Detailed model for grades for case 1

		before isolation	during isolation
1	independent work	47	26
A		8	4
B	eating food	9	3
C	using the toilet	11	7
D	Cleanliness	8	5
E	The appearance	0	0
F	Garment care	11	7
G	Dressing and undressing	0	0
H	moving around	0	0
2	Independent work	22	13
A	physical growth	6	6
B	Sensory development	16	7
3	Motor skills growth	2	0
A	The economic activity	0	0
B	Money handling and budget planning	2	0

4	Buying skills	11	2
A	Language improvement	9	1
B	expression	2	1
C	comprehension	0	0
	The increase of social language	8	3

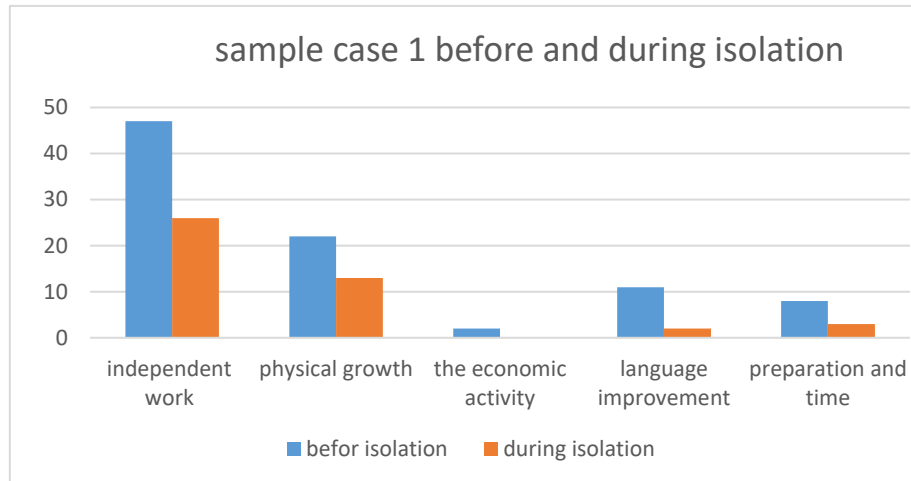


Figure 1.Case 1

As for the results of the researcher's follow-up of the cases, she noticed the presence of repeated complaints from families. The researcher identified these phenomena in two dimensions:
 Child problems:

- Refusing the types of food offered according to what was available at the time of isolation, and searching for the child's favorite food, which was at times difficult to manage because of isolation and the closure of shops.
- Screaming and crying continuously without stopping.
- Inability to express, and the matter turns into self-harm, harm to others and domestic vandalism.
- Frequently repeating stereotypical behaviors, and the family finds it difficult to stop him or engage him in an alternative activity.
- Loss of skills in communication, language, and interaction with others.
- Great preference for screens.
- Sleep disorders, either sleeping for long periods, or not sleeping for long periods.
- Loss of weight due to not eating and increasing stereotypical behaviors.

Family issues:

- Home isolation was a source of great stress and anxiety for all families, but the presence of a child with ASD had a great psychological impact on the families.
- Because the family did not learn how to deal well with their child, and they depended very much on specialists. When the centers were forced to close completely, the families discovered that they could not deal with them. Whereas normally, the child would return from

the center exhausted and empty of energy, eat and sit for a while and watch screens with them until he/she falls asleep.

- The family felt a state of sadness, anxiety, guilt, fear for the child's future, and severe psychological pressure in case the children's behavioral problems increased.
- The researcher's meetings with the family were a psychological outlet for them to relieve psychological pressure, and to obtain instructions for intervention with the child.

Discussion

This study described the negative impact of the Corona pandemic on children with ASD and their families during the lockdown in Egypt. This period had greatly affected children from the psychological and behavioral side. Undesirable behaviors, crying and screaming due to the interruption in daily routine, sensory problems, and verbal communication problems. In addition, families with children with ASD faced many challenges because they were fully responsible for their children after they had complete dependence on specialists. It was early on during the pandemic that families were concerned about the child staying home all the time not being able to go out. Later on, families had other problems of not being able to deal with the ASD children, especially that they had more behavioral problems, aggression, eating and sleeping disorders, sensory disturbances, and the loss of skills they acquired because of not continuing the training. As a result, families resorted to consultations from the technical officials in the center on how to intervene positively, and there was a need for a complete and detailed explanation of intervention methods through video conferencing platforms, including scheduled meeting on Zoom. However, the prearranged and agreed-upon meeting represented an additional burden to the families. Therefore, some families stopped attending training sessions and gave children unlimited access to screens to reduce anger outbursts and behavioral problems. Hence there is an urgent need to involve the family in the intervention to a large capacity and in depth, to learn the scientific method of dealing with its own child.

Conclusion

The study concluded that the pandemic significantly affected children with ASD and their families. During the pandemic, children lost many social, behavioral, linguistic, sensory, selfcare, and communication skills due to the lockdown and not being able to receive adequate services. Therefore, it was necessary to have an alternative to providing care directly, using technology to guide families remotely and give them adequate support to help them accept their new responsibility. Despite all these attempts, the problem remained in the urgent need for direct education and heavy reliance on the experts for early diagnosis and rehabilitation services. This reveals that special education remains unique even in times of crisis.

Therefore, the researcher had to think of a way to overcome this crisis with families in the event of the continuation of the epidemic, or the emergence of new epidemics. Because of this study and its findings, the researcher launched the Specialized Mother Initiative. This is a comprehensive humanitarian specialist initiative that stemmed from a humanitarian societal responsibility, aiming to raise the awareness of a family that has a child with a disability on how to deal with it in a scientific and systematic manner that is beneficial to the child, the family and society. This is because the family is the real hero in the field of special education. It bears great concerns and challenges, and there is a significant need for support for families. Through the launch of a Facebook group, more than 50 Egyptian volunteers with special education qualification and experience, from more than 30 Egyptian institutions collaborated in organizing training for mothers with children with special educational needs throughout Egypt, including Cairo - Giza - Qalyubia - North Sinai - Aswan - Assiut - Sohag - Alexandria - Sharkia - Gharbia - Menoufia - Dakahlia - Damietta and- Fayoum.

Because of this study the findings initiated this this humanitarian initiative, with the help of 50 exporters and developed a program to teach them how to detect a disorder or deficiency in their child, and where and when to go for examination. This enables early intervention to support and empower mothers with

practical tools on how to face the challenges during the period of being at home, with support from a scientific method of follow-up the psychological, educational, religious and values of the child within the context of the family.

The initiative was also interested in transferring the experiences of the volunteer team to families in evaluation, diagnosis, rehabilitation and answering family questions through direct meetings that continue to occur once a month, and online meetings that take place four times a month via Zoom. Thus, the result of the study has a significant impact on families in the Itqan Learning Centre and beyond and are still ongoing. The volunteers continue to address the challenges that were raised during the lockdown and other challenges daily since restrictions have been lifted. It is hoped that this will continue, and the initiative will benefit more families, mothers due to the responsibilities that fall on them within the cultural context of Egypt and the Arab society.



Figure 2. Logo of the Specialized Mother Initiative.

Limitations and recommendations

Research limitations:

1. Observations and meetings were held online due to the national lockdown. It would have been best for observations to take place in person. Of course, due to the restrictions this was not possible and beyond the scope of this research.
2. Because the sample members are from the center and because the researcher is familiar with them, this form facilitated the conduct of the research and the participation of the family in it. However, if this was not the case, it would have been difficult to convince the families.
3. The number reached 20 families only, because some families did not have an internet network that would allow them to attend meetings.
4. The research sample ranges from 4 to 10 years which is the most regular and acceptable age in the center. Children outside this age range may also be affected by the lockdown, but this study had no access to other children but the center.

Recommendations:

Complementing this effort, the research recommends:

1. The need to train families to deal with their children and to know all the details of the child's strengths and weaknesses and the child's training needs.
2. The need for special education to move beyond the narrow tunnel (table and chairs) to the vast technological space that relies on mobile applications and electronic platforms that benefit rehabilitation, diagnosis, and training for mothers.
3. Full community awareness of the issues of people with disabilities and the provision of means to facilitate life for them, for example, by providing shops selling dairy products and eating without casein and gluten until the time of home quarantine.
4. Supporting the private family psychologically, as it suffers more than ordinary families by highlighting their suffering and challenges through the media. This will represent psychological support for them.

Acknowledgments

Sincere thanks, appreciation, and gratitude to the Egyptian families who participated in the research, and all thanks to the members of the initiative who took the responsibility of volunteering to train the mothers. Also, sincere thanks to the institutions that opened their doors to the team of trainers in order to transfer the knowledge, reduce the burden, and answer the families' questions. I also extend my sincere thanks and appreciation to the Re-KnoX team and their committee members. I was very pleased to attend the 3-day inauguration conference held in Cairo in August 2022, where I presented this paper.

They have been supportive throughout the process of submitting the abstract and translating, reviewing, and editing this paper.

References

- Abdullah Muhammad, A., Adel, & Abul-Magd Muhammad. (2020). Gilliam Estimated Scale for Diagnosis of Symptoms and Severity of Autism Disorder - GARS-3 Edition. *Journal of Childhood and Education (Alexandria University)*, 42(1), 41-76.
- Action at a Distance: Geriatric Research during a Pandemic—PubMed. (n.d.). Retrieved 11 October 2022, from <https://pubmed.ncbi.nlm.nih.gov/32207542>
- Ameis, S. H., Lai, M.-C., Mulsant, B. H., & Szatmari, P. (2020). Coping, fostering resilience, and driving care innovation for autistic people and their families during the COVID-19 pandemic and beyond. *Molecular Autism*, 11(1), 61. <https://doi.org/10.1186/s13229-020-00365-y>
- Asbury, K., Fox, L., Deniz, E., Code, A., & Toseeb, U. (2021). How is COVID-19 Affecting the Mental Health of Children with Special Educational Needs and Disabilities and Their Families? *Journal of Autism and Developmental Disorders*, 51(5), 1772–1780. <https://doi.org/10.1007/s10803-020-04577-2>
- Baribeau, D. A., Vigod, S., Pullenayegum, E., Kerns, C. M., Mirenda, P., Smith, I. M., Vaillancourt, T., Volden, J., Waddell, C., Zwaigenbaum, L., Bennett, T., Duku, E., Elsabbagh, M., Georgiades, S., Ungar, W. J., Zaidman-Zait, A., & Szatmari, P. (2020). Repetitive Behavior Severity as an Early Indicator of Risk for Elevated Anxiety Symptoms in Autism Spectrum Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 59(7), 890-899.e3. <https://doi.org/10.1016/j.jaac.2019.08.478>
- Chen, R. S. (2021). The researcher's participant roles in ethical data collection of Autistic interaction. *Social Interaction. Video-Based Studies of Human Sociality*, 4(2).
- Colizzi, M., Sironi, E., Antonini, F., Ciceri, M. L., Bovo, C., & Zocante, L. (2020). Psychosocial and Behavioral Impact of COVID-19 in autism spectrum disorder: An Online Parent Survey. *Brain Sciences*, 10(6), 341. <https://doi.org/10.3390/brainsci10060341>
- Coronavirus Disease 2019 (COVID-19) and Mental Health for Children and Adolescents | Adolescent Medicine | JAMA Pediatrics | JAMA Network. (n.d.). Retrieved 11 October 2022, from <https://jamanetwork.com/journals/jamapediatrics/fullarticle/2764730>
- Cross, S. P., & Hickie, I. (2017). Transdiagnostic stepped care in mental health. *Public Health Research & Practice*, 27(2), 2721712. <https://doi.org/10.17061/phrp2721712>
- Curtin, C., Hubbard, K., Anderson, S. E., Mick, E., Must, A., & Bandini, L. G. (2015). Food Selectivity, Mealtime Behavior Problems, Spousal Stress, and Family Food Choices in Children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45(10), 3308–3315. <https://doi.org/10.1007/s10803-015-2490-x>
- Eshraghi, A. A., Li, C., Alessandri, M., Messinger, D. S., Eshraghi, R. S., Mittal, R., & Armstrong, F. D. (2020). COVID-19: Overcoming the challenges faced by individuals with autism and their families. *The Lancet Psychiatry*, 7(6), 481–483. [https://doi.org/10.1016/S2215-0366\(20\)30197-8](https://doi.org/10.1016/S2215-0366(20)30197-8)
- Fitzpatrick, S. E., Srivorakiat, L., Wink, L. K., Pedapati, E. V., & Erickson, C. A. (2016). Aggression in autism spectrum disorder: Presentation and treatment options. *Neuropsychiatric Disease and Treatment*, 12, 1525–1538. <https://doi.org/10.2147/NDT.S84585>
- Goswami Vernal, T. (2021). SELF CARE, MENTAL HEALTH AND COVID-19: AN EXPLORATORY STUDY OF THE COPING STRATEGIES OF CAREGIVERS OF INDIVIDUALS WITH AUTISM DURING THE PANDEMIC (IN HYDERABAD, INDIA). *BAU Journal-Society, Culture and Human Behavior*, 2(2), 9.



- Greaney, A. M., Sheehy, A., Heffernan, C., Murphy, J., Mhaolrúnaigh, S. N., Heffernan, E., & Brown, G. (2012). Research ethics application: A guide for the novice researcher. *British Journal of Nursing*, 21(1), 38-43.
- Faraj, Safutto. (2011). a. Satford-Biniah Measures of Intelligence (Fifth Image), Examiner's GuideCairo.
- Hill, A. P., Zuckerman, K. E., Hagen, A. D., Kriz, D. J., Duvall, S. W., Van Santen, J., ... & Fombonne, E. (2014). Aggressive behavior problems in children with autism spectrum disorder: Prevalence and correlates in a large clinical sample. *Research in autism spectrum disorder*, 8(9), 1121-1133.
- Howlett, M. (2022). Looking at the 'field' through a Zoom lens: Methodological reflections on conducting online research during a global pandemic. *Qualitative Research*, 22(3), 387-402.
- Jacques, C., Saulnier, G., Éthier, A., & Soulières, I. (2022). Experience of Autistic Children and Their Families During the Pandemic: From Distress to Coping Strategies. *Journal of Autism and Developmental Disorders*, 52(8), 3626–3638. <https://doi.org/10.1007/s10803-021-05233-z>
- Keenan, B. M., Newman, L. K., Gray, K. M., & Rinehart, N. J. (2016). Parents of Children with ASD Experience More Psychological Distress, Parenting Stress, and Attachment-Related Anxiety. *Journal of Autism and Developmental Disorders*, 46(9), 2979–2991. <https://doi.org/10.1007/s10803-016-2836-z>
- Lai, M.-C., Anagnostou, E., Wiznitzer, M., Allison, C., & Baron-Cohen, S. (2018). Evidence-based support for autistic people across the lifespan: Maximizing potential, minimizing barriers, and optimizing the person-environment fit. <https://doi.org/10.31219/osf.io/8z5rv>
- Lai, M.-C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *The Lancet Psychiatry*, 6(10), 819–829. [https://doi.org/10.1016/S2215-0366\(19\)30289-5](https://doi.org/10.1016/S2215-0366(19)30289-5)
- Lindgren, S., Wacker, D., Schieltz, K., Suess, A., Pelzel, K., Kopelman, T., Lee, J., Romani, P., & O'Brien, M. (2020). A Randomized Controlled Trial of Functional Communication Training via Telehealth for Young Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 50(12), 4449–4462. <https://doi.org/10.1007/s10803-020-04451-1>
- lobodin, O., Heffler, K. F., & Davidovitch, M. (2019). Screen Media and Autism Spectrum Disorder: A Systematic Literature Review. *Journal of Developmental & Behavioral Pediatrics*, 40(4), 303–311. <https://doi.org/10.1097/DBP.0000000000000654>
- Must, A., Eliasziw, M., Phillips, S. M., Curtin, C., Kral, T. V. E., Segal, M., Sherwood, N. E., Sikich, L., Stanish, H. I., & Bandini, L. G. (2017). The Effect of Age on the Prevalence of Obesity among US Youth with Autism Spectrum Disorder. *Childhood Obesity*, 13(1), 25–35. <https://doi.org/10.1089/chi.2016.0079>
- NESH, T. (2022). Guidelines for Research Ethics in the Social Sciences and the Humanities.
- Nevill, R. E., Lecavalier, L., & Stratis, E. A. (2018). Meta-analysis of parent-mediated interventions for young children with autism spectrum disorder. *Autism*, 22(2), 84-98.
- Nicol, G. E., Piccirillo, J. F., Mulsant, B. H., & Lenze, E. J. (2020). Action at a distance: geriatric research during a pandemic. *Journal of the American Geriatrics Society*, 68(5), 922-925.
- Racine, N., McArthur, B. A., Cooke, J. E., Eirich, R., Zhu, J., & Madigan, S. (2021). Global prevalence of depressive and anxiety symptoms in children and adolescents during COVID-19: a meta-analysis. *JAMA pediatrics*, 175(11), 1142-1150.
- Resilience in autism: Research and practice prospects—Meng-Chuan Lai, Peter Szatmari, 2019. (n.d.). Retrieved 11 October 2022, from <https://journals.sagepub.com/doi/full/10.1177/1362361319842964>
- Roszkowski, M. J., & Bean, A. G. (1980). The Adaptive Behavior Scale (ABS) and IQ: How much unshared variance is there? *Psychology in the Schools*, 17(4), 452-459. translated Safwat Farag, Nahed Ramzy, 1985.



Saidin, K. (2016). Insider researchers: Challenges & opportunities. *Proceedings of the ICECRS*, 1(1), v1i1-563.

Schreck, K. A., & Richdale, A. L. (2020). Sleep problems, behavior, and psychopathology in autism: Interrelationships across the lifespan. *Current Opinion in Psychology*, 34, 105–111. <https://doi.org/10.1016/j.copsyc.2019.12.003>

Yılmaz, B., Azak, M., & Şahin, N. (2021). Mental health of parents of children with autism spectrum disorder during COVID-19 pandemic: A systematic review. *World journal of psychiatry*, 11(7), 388.

Biographical notes:

Dr.. Doaa Sami Said holds a PhD in Special Education from the Faculty of Graduate Studies of Education, Cairo University, with the credit hour system, with an excellent grade, 2021.

She holds a master's degree in special education from the Faculty of Graduate Studies of Education, Cairo University, with the credit hour system, with an excellent grade, 2018.

- Certified trainer in the field of special education, and I have 60 training programmes for children with disabilities, autism, and education.
- Technical director and founder of the House of Learning Excellence Foundation in the Arab Republic of Egypt, and many other centres.
- 15 years of experience as a Special Educational Needs Practitioner with children with ASD.