

Reflections of COVID-19 Pandemic on Autism Spectrum Disorder: A Descriptive Case Study

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Abstract: The aim of this study was to explore type of studies implemented for the autism spectrum disorders (ASD) community by institutions that directly deal with ASD during the COVID-19 pandemic in Turkey and in the world. The descriptive case study design was used in the study. The contents on the websites of the institutions were analyzed through document analysis. According to the results, it was observed that the data consisted of supporting contents related to education, health, and public policies regarding the COVID-19 process and that the contents were frequently presented through webinars, visual representations, electronic text sources, online communication platforms, and social media environments. During this process, informative studies were frequently carried out and practical studies were rarely conducted. While it is considered that institutional studies both in Turkey and in the world may serve as an example to other institutional studies, it is considered that the diversity of these examples should be increased through cooperation between institutions.

Keywords: Coronavirus, COVID-19, pandemic, autism spectrum disorders, parents, special education, institutions

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Introduction

As a result of the coronavirus (COVID-2019) epidemic that emerged on December 2019 in China and rapidly increased mortality, the World Health Organization (WHO) identified COVID-19 as a pandemic on January 30, 2020 (WHO, 2020). Due to the rapid spread of COVID-19 via human contact, a number of measures were taken to control the pandemic. In addition to curfews, self-isolation, 14-day quarantine, and social contact, gathering spaces were also closed. Due to these measures taken to slow the spread of the Covid-19 pandemic, educational institutions were closed in several nations (Figure 1). Consequently, the education of 1.6 billion students, equal to 90% of the global student population, was interrupted (UNESCO, 2020a; 2020b; UNICEF, 2020).

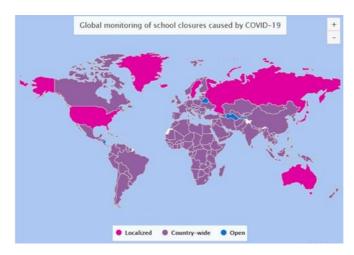


Figure 1. Global school closures as of April 15, 2020 (UNESCO, 2020a)

Thus, emergency distance education methods were adopted immediately to provide online and offline educational content and to prevent the interruption of educational services (Bozkurt & Sharma, 2020a, 2020b; Bozkurt et al., 2020). During the pandemic, parents who were isolated at home with their children assumed certain social responsibilities as well as educational roles (Bozkurt et al., 2020; Devercelli, 2020). Especially women who provided childcare were disadvantaged due to the increased pressures (Bozkurt et al., 2020). During the COVID-19 pandemic, all children and parents were affected; however, the children and parents with special needs and require support were the most affected group (Bozkurt et al., 2020; Guterres, 2020).

Immediate measures such as staying at home, complying with the rules at home (i.e., disinfecting hands, wearing masks, staying at home), and adopting new routines could lead to difficulties especially for individuals with autism spectrum disorder (ASD) who experience problems in comprehending sudden stressful situations, understanding social-communication cues, and who are extremely resistant to changes in routine (den Houting, 2020; Weir et al., 2020). Routines that help us organize our domestic, educational, and professional life are very important to feel the confidence that is



derived from regular, predetermined, and stable activities (Bozkus-Genc, 2019). The unexpected changes in these routines and rules, which are important for individuals to feel comfortable and safe, lead to various psychological and physical problems such as trauma, depression, and psychological pressures even in children with typical development (Cao et al., 2020) and become difficult to understand and manage for children with ASD and their parents who are strictly bound by routines (Altable et al., 2020; Narzisi, 2020). The limitations encountered by children with ASD and the deterioration of their routines are considered difficult to manage (e.g., fear from the virus, disappointment, deprivation, finding it boring to conduct homeschooling, and feelings of anger, etc.) (Stankovic et al., 2020; Tarbox et al., 2020). In a study conducted by Stankovic et al. (2020), it was reported that parents with children with ASD were scared about their children to exhibit problem behavior such as overselectiveness about food or insistence on eating the same food. When asked about their greatest concern about the pandemic and the emergency, parents stated that they were worried about a possible increase in or intensification of ASD symptoms due to changes in daily routine (e.g., non-attendance to school or kindergarten, continuous repetition of news reports on infection, etc.) and the child losing the previously acquired or learned skills rather than the infection itself. Since institutional interventions have totally changed in environments such as schools, hospitals, and businesses, the social support provided for the children with ASD and their parents who receive specialist support from relevant institutions in many areas (e.g. social-communication, self-care, vocational, psychological, etc.) is expected to decrease and these groups are expected to exhibit higher levels of stress (Altable et al., 2020; Bakér-Ericzen et al., 2005; Stankovic et al., 2020). Considering that individuals with ASD are more likely to develop anxiety, distress, and depression in the face of uncertainties (Mazefsky et al., 2008; Yirmiya & Shaked, 2005), it is likely that limitations in daily life would disrupt the daily routine and would affect the psychological health of several individuals with ASD (Wright et al., 2020). The present and inadequate support provided for these families, the feelings of helplessness, and various difficulties that these families experienced in the past deteriorated during the pandemic (Huremović, 2019). Thus, it was reported that it was important to quickly create new and functional resources to ensure the collaboration between parents, therapists, and researchers for the safety and peace of this group of children and allow them to quickly adapt to the "new normal" during the COVID-19 pandemic (Tarbox et al., 2020).

It is important for the specialists who work with children, adolescents and adults with ASD and their families to seek various means of support to reach these groups in these challenging and uncertain times (Narzisi, 2020). During the pandemic and the post-pandemic periods, everyone tries new methods for the individuals with ASD and their parents to communicate with each other and provide alternative ways to access support, therapy, education, and social services. Thus, these challenging times and changes could also provide an opportunity for several problems associated with ASD. ASD advocates and/or related institutions that have spent efforts to develop means to provide access for individuals with ASD to social areas, health services, education, and employment for several years could realize and improve certain ideas such as online



distance education, and development of support appointments, evaluation, communities that they could not implement before (Cassidy et al., 2020). Thus, several institutions that advocated the rights of individuals with ASD (e.g., Autism Society, Autism Speaks, Seed Autism Foundation, etc.) conducted various studies and provided support for parents and individuals especially in educational-behavioral areas during the pandemic. In these extraordinary times, these studies conducted by institutions are more significant than before; these are also important in laying the foundation and providing guidance for future work, raising awareness about other institutions in the field, and revealing the scale of the cooperation. Due to the possibility of future waves of the pandemic or similar challenges (e.g., natural disasters such as earthquakes, floods, etc.) and interruption of education, it was suggested that better strategic plans are required for ASD (Huremović, 2019). Thus, it is necessary to present the studies conducted by these institutions directly working in the field of ASD for individuals with ASD and their families. Based on these ideas, the present study aimed to discuss the studies conducted by international and domestic ASD organizations to benefit the ASD community during the COVID-19 pandemic. Thus, the following research problems were determined to inquire the studies conducted by ASD organizations in the world and in Turkey to inform individuals with ASD, their parents, and other care/service providers during the COVID-19 pandemic:

- 1. What kind of support services are provided?
- 2. Which support materials and media are utilized?
- 3. What is the level of coordination between the institutions?

Methodology

The Research Design

The current research was a descriptive case study, a qualitative research method (Yin, 1984). Case study is a research method that allows the researcher to investigate a phenomenon or an event that was not controlled by the researcher in depth based on "why" and "how" questions (Yıldırım & Şimsek, 2016). The main aim is to discover, describe, and interpret a case as is (Yin, 1984). On the other hand, a descriptive case study aims to describe an intervention, a phenomenon and a real-life context in which it emerges (Merriam, 1998; Yin, 1984). Thus, the study aimed to determine the work conducted by domestic and international ASD organizations during the COVID-19 pandemic, which is a current phenomenon.

Data Collection and Analysis

The study data were collected and analyzed with document review (Bowen, 2009). The document review process included four stages: in the first stage, the inclusion and



exclusion criteria were determined for the domestic and international ASD organizations and COVID-19. The institutions selected for review were determined based on the following criteria:

- An organization that provides informative content and material on educational or health services associated with ASD and COVID-19.
- The presence of online educational modules for individuals with ASD and their parents.
- A local or global pioneer organization that advocates ASD rights.

Exclusion criteria were determined as follows:

- Providing only content on COVID-19-related health services
- Conducting work that aims to provide information for general population
- Focus on individuals with special needs instead of individuals with ASD
- Providing only news reports or announcements instead of informative content
- Non-governmental ASD organizations or ASD associations

In this context, eight institutions that met the inclusion criteria were determined for in depth analysis: "Autism Awareness, Autism Speaks, Autism Society, Autistica, Center for Autism and Related Disorders (CARD), National Autism Center (NAC), National Autistic Society, and Seed Autism Foundation." There were several small associations or organizations in Turkey or elsewhere that could not be included due to the selection criteria. For example, in Turkey, it was observed that Turkish Autism Council, Autism Society Federation (ODFED) and Autism Personal Support Foundation (OBIDEV) provided brief notices or announcement associated with the COVID-19 pandemic and individuals with ASD. Furthermore, certain institutions [e.g., World Health Organization (WHO), Center for Disease Control and Prevention (CDC), American Psychiatric Association (APA)] were excluded on the grounds that they provided only general information about COVID-19 instead of special information pertaining to ASD and COVID-19. In the second stage, the content of all documents such as biographical articles, interviews, videos, photos, webinars, blog posts, online training programs, news, reports, guides, books, articles etc. found on the websites of the institutions included in the study were reviewed in detail as primary data sources. Furthermore, associated links, corporate posts on social media such as Facebook, Instagram, and Twitter were also included in the analysis to support the primary data source. In the third stage, the files collected from the relevant institutions were filed for analysis. The files were uploaded to Google Drive that allows the researchers to store documents on the cloud, share files and organize documents for collaboration. In the final stage, the study data collected from the institutions were analyzed with document analysis. Initially, all website content was transferred into documents and the associated codes and themes were determined based on the document analysis, and finally, the themes were edited. The authors participated in this process via teleconference, and



disagreements were resolved by discussions. The themes were visualized and presented as figures and explained in detail in the findings section.

Validity and Reliability

One of the methods to ensure validity in qualitative studies is to report the data in detail (Yıldırım & Şimşek, 2016). Thus, institutional documents about COVID-19 and ASD were analyzed and reported in detail, and data were also presented for the readers to add their comments. Another approach used to ensure and improve reliability in qualitative studies is diversification (Seggie et al., 2017; Oppermann, 2000; Yıldırım & Şimşek, 2016). In the present study, author diversification was adopted by reaching different perspectives and views of experts.

Thinking with the data is an extremely important issue in data analysis to ensure content integrity (Glesne, 2011). Otherwise, data correlations could be missed, or themes that are not related to the study aim may be determined (Bryman, 2012; Seggie et al., 2017). Thus, the codes and themes were determined with the collaboration of all authors via teleconference during the analysis to ensure the content integrity based on the study aim. Furthermore, coding reliability was established by an independent expert.

In case studies, similar to the other qualitative research methods, the role of the author is quite important in data collection. The present study authors have published various academic studies on ASD and/or qualitative research. It was suggested that the role of the authors provided an endogenous Turkish and global perspective, and the study data were collected from primary resources, strengthening the research. Furthermore, to ensure the study reliability, an audit trail, where an independent reader with experience on the study topic verified the study findings by following the method employed by the authors, was employed.

Findings

In the present study that aimed to determine the work conducted by Turkish and international ASD organizations for ASD community during the COVID-19 pandemic, the work conducted by eight organizations that met the selection criteria were analyzed. The information about these organizations is presented in Figure 2.





Figure 2. Analyzed institutions

As seen in Figure 2, all institutions that shared content to assist individuals with ASD during the COVID-19 pandemic were those that directly served the global autism community. The analysis of the review reports (raw data) for each institution revealed the main themes of (1) assistance for the COVID-19 pandemic, (2) the utilized support material and media, and (3) the interinstitutional cooperation. These main themes could differentiate in sub-themes and codes for each institution based on their work. In the following section, the findings associated with the assistance commonly provided by all institutions and those unique to certain institutions, the type and the media of the support material employed by the institutions, and interinstitutional cooperation are presented.

Common Support Services Provided by the Institutions

The review of the common support services provided by the institutions demonstrated that they provided similar content, especially in the fields of education and health. Furthermore, each institution had online support lines to communicate with individuals with ASD and their families. Common support services offered by institutions are presented in Figure 3.

As seen in Figure 3, the similar support services could be categorized in three main themes: education, health, and support lines. Educational content included four subthemes: coping with the pandemic, uncertainty and the balance in domestic life, work-personal life balance of adults with ASD, and adaptation to the new normal. In educational content, all institutions provided visuals that reflected basic rules such as the required hygiene for protection from the COVID-19 virus, social distancing, and the isolation at home. Based on the possible effects of the uncertainty on individuals



with ASD, the institutions developed content on issues such as behavioral management based on evidence-based applications and new routines in coping with uncertainty. In the employment of individuals with ASD, content associated with telecommuting and the development of new work routines were also provided by all institutions. Furthermore, the novelties that would be introduced by the process called the "new normal" and how to prepare for the new normal were also addressed.



Figure 3. Similar support services provided by the institutions

The review of the support services provided in the field of health revealed psychological health assistance was developed to cope with stress, anxiety, and to manage the crisis induced by the pandemic. Access to various comforting activities were provided, and the links to relaxing artistic, musical, and travel-related applications that could be selected based on personal preferences were provided to improve psychological health and to support the development of new domestic routines. Furthermore, telehealth applications were provided to access healthcare services. Information on physical personal and environmental hygiene was developed to control the pandemic and to ensure permanent behavioral changes during the transition to the new normal.

Always accessible ASD support lines were provided to establish effective and continuous communication with individuals with ASD and their families. These lines were developed specifically for the pandemic by certain institutions under different names such as Autism Support Line, Life and Crisis Support Line, Autism Learning Line, and certain others utilized the existing live chat line on their web sites or social media.



Unique Support Services Provided by the Institutions

Certain institutions also developed unique content in the fields of education, health and public policy. As seen in Figure 4, Autism Awareness provided educational content, tips, and an online platform for individuals with ASD to communicate with each other. CARD offered virtual socialization opportunities such as online drama courses, musicals, life skills workshops, and virtual nature trail excursions for individuals with ASD who stay at home during the pandemic. Furthermore, CARD was the only institution that called for the participation of the online community and developed information, news reports and advertising campaigns for this purpose. Autistica, on the other hand, focused on the interruption of diagnostic and evaluation services during the pandemic, which was one of the most important issues for individuals with ASD, and provided information about the diagnostic and evaluation alternatives during this period. Furthermore, they emphasized the increase in mortality rate among nursing homes residents with ASD.

The Autism Society provided assistance for families for school closures after the schools were closed with a sudden decision during the pandemic, leading to changes in the daily routine of the individuals with ASD as they started to spend all their time at home. Supportive content on school closure and information on how to continue education at home were provided.

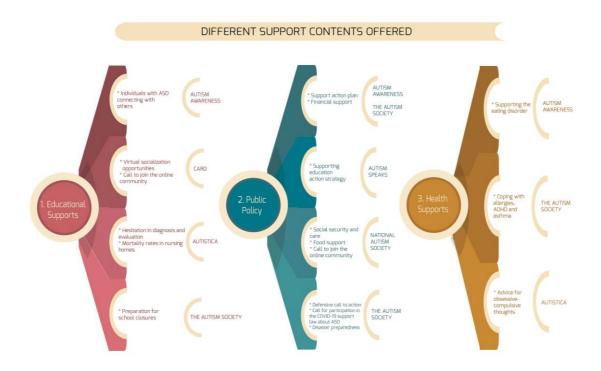


Figure 4. Different support services provided by the institutions



Employed Support Material and Media

The institutions reviewed in the study employed various online media and material to present the COVID-19 support services. These support material and media are summarized in Figure 5.

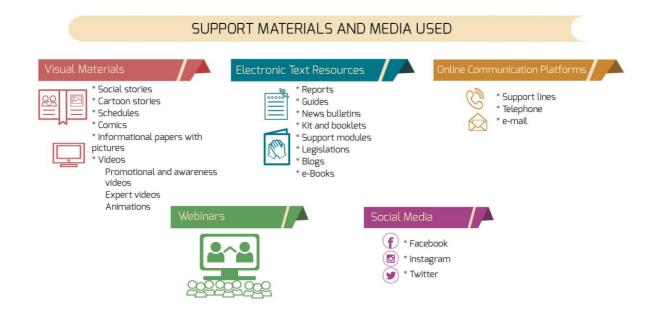


Figure 5. The support material and media employed by the institutions

As seen in Figure 5, the institutions employed support material and media such as visual stories, electronic texts, online communication platforms, webinars, and social media posts. It should be underlined that visual stories frequently included social stories and charts, and the content was supported by visuals whenever possible. In addition to the promotional videos that aimed to raise awareness about ASD, short and long videos and animations with professional narration on various educational topics were also employed. Furthermore, webinars were organized in the live broadcast format, where the participants could be registered, and these seminars were recorded and provided for future use. Unlike other institutions, Autism Awareness provided animated stories, National Autistic Society developed animations, and Autism Society included cartoons.

Institutions conducted effective information sharing activities using reports, guides, news bulletins, kits and booklets, support modules, e-books and information on legal regulations, and interactive blogs on their web sites. NAC employed limited electronic material and media such as manuals and newsletters.

The institutions employed online communication platforms such as phone lines, live chat, and e-mail facilities for communication and support line purposes in addition to visual stories, webinars, and electronic texts. Similarly, organizations actively posted on their social media accounts for both to communicate and share content with their



audience. The analysis based on the institutions revealed that the most diverse support material and media use were exhibited by the Autism Society, National Autistic Society, Autism Awareness, and Autism Speaks. Seed Autism Foundation, on the other hand, provided Educational Information Network videos in collaboration with the Ministry of National Education and employed kits, booklets, and mobile applications on COVID-19.

Interinstitutional Cooperation

The institutions reviewed in the study also provided links to other institutions and material developed by different institutions on their web sites. The interinstitutional cooperation is presented in Figure 6.



Figure 6. The support content developed by other institutions and shared by the reviewed institutions

The reviewed institutions employed the information provided by the WHO, CDC, and UNICEF web sites about the pandemic and prevention in their content on health. Furthermore, the institutions employed the health information provided by APA, NHS, IRS, CMS, NICE, and Careers UK during the pandemic. NPDC, Autism Europe, Autism Resource Center, IPSEA, ACL, Stage Learning, SAMHSA, GoNoodle, Pinterest, Scouts, Educatingallearners (EALA), and MNE were the prominent institutions that provided educational content. The public policy content provided by large institutions such as Feeding America and Food Pantries included information about soup kitchens and nutritional support. The institutions that cooperated with other institutions the most included the National Autistic Society and Autism Society. Also, it could be suggested that among other collaborating institutions, WHO, CDC, and UNICEF were the leading institutions and cited more than one institution on their web sites.



Discussion and Conclusion

Based on the findings of the present study, conducted to determine the support provided for individuals with ASD by institutions that conducted COVID-19 studies, it was observed that the eight institutions included in the present study provided several facilities for the communities interested in ASD, including individuals with ASD, their families, and specialists. The analysis of the work undertaken by these institutions revealed three main themes: support information, employed support material and media, and interinstitutional cooperation; and common and unique efforts of these institutions are presented.

The review of the support services offered by the institutions demonstrated that all institutions focused on the understanding and infection prevention methods, domestic crisis and coping with crisis, changes in routine, behavioral and psychological health problems, and methods to cope with these problems. The institutions focused on these issues since due to the COVID-19 conditions, home environment became the only environment where the family members spent time (degli Espinosa et al., 2020). It was necessary to develop new routines/activities at home. However, due to limited delivery of non-essential items, parents experienced difficulties in providing toys or other products to ensure that children with ASD could spend time with their siblings and develop new interests, and develop novel means (degli Espinosa et al., 2020). Thus, it could be suggested that parents could not develop new routines due to the limited environmental and material facilities at home, and children with ASD experienced difficulties in coping with the stress and anxiety induced by the disruption of their routine. Second, although the COVID-19 pandemic had an extraordinary impact on the lives of families all over the world, parents of children with ASD were suddenly deprived of services and personal support facilities such as practical behavior analysis, and the education of their children became a serious problem (Tarbox et al., 2020). In this process, distance education could be very challenging and destructive for children with ASD and their parents. This sudden change also imposed further responsibilities on parents such as simultaneous roles as a parent, a special education teacher for their children with ASD, and the caretaker of their other children while conducting their businesses at home. In this process, it was a fact that families needed guidance from a special education specialist for the acquisition of skills and behavior necessary for the development of their children and to reduce problem behavior. Third, both children with ASD and their parents experienced stress. It was reported that the parental stress level was associated with the type of disability or disorder of the child (Gupta, 2007). Mothers of children with ASD experience higher levels of stress when compared to mothers of children with other developmental disabilities (Abbeduto et al., 2004; White & Hastings, 2004) or children with typical development (Baker Ericzén et al., 2005; Yamada et al., 2007). It is known that individuals with ASD, as well as their parents, are more stressed and suicidal when compared to individuals with typical development (Bishop-Fitzpatrick et al., 2017; Cooper et al., 2017). It was reported that adults with ASD experience painful effects of social isolation and solitude, which leads to a real impact on their psychological health and the risk of suicidal tendencies (Hedley et al.,



2018; Pelton et al., 2020). The impact of the pandemic on the mental health of adults with ASD is truly worrisome. Thus, the quick response of the institutions to the needs of the families was remarkable. However, the informative quality of the support services is also an important part of discussion. It is very important to inform the parents and individuals; however, the implementation of this information could be challenging for the parents. Therefore, applied support services training is extremely important for the parents. Although it could be argued that a practical training could not be planned for a sudden pandemic, this issue should be emphasized during the transition to the new normal.

Providing employment of information for adults with ASD are particularly important. Individuals with ASD, similar to any adult individual, may also have concerns about employment. Individuals with ASD experience difficulties in coping with employment anxiety after graduation. Especially due to additional challenges introduced by the pandemic, the stress they experience about employment was compounded exponentially. Informative support on coping mechanisms is required. It is necessary to identify and discuss the challenges and opportunities that COVID-19 pandemic introduced for adults with ASD based on various perspectives (Cassidy et al., 2020). Especially for individuals with ASD, institutions should identify the problems specific to ASD and provide further information and support services about businesses and job opportunities suitable for these individuals, develop collaborative employment projects for individuals with ASD, improving the participation of these individuals in professional and social life.

Transition to the new normal is another issue of current debate. Associated changes, aptly christened the new normal, have been gradually implemented globally. The transition to the new normal is a novel experience for all. Thus, the focus should be on the preparation of the individuals with ASD for the new normal. Measures that should be adopted during quarantine and outside the home during the transition to the new normal introduced new duties and responsibilities for the individuals with ASD. Certain children could insist on pre-pandemic rules during the transition. For some individuals with ASD, this may manifest itself as challenging behavior in daily life. During the instruction of the rules that these individuals experience difficulty with, the location of learning, the instructor, daily activities, implementation of these measures, and associated emotions should be described clearly (Tarbox et al., 2020).

For them to get through this process easily, parents have a great responsibility. The implementation of domestic measures for the preparation of these individuals for new life experiences would surely be difficult, complex, tiring, and introduce additional burden for the parents. Thus, institutional support could be needed. However, although the transition to the new normal has begun, it is necessary to consider the possibility of experiencing the same issues in the future. Turkey and other countries could experience epidemics or natural disasters in the future. Therefore, information should be provided in advance about the measures that should be implemented during extraordinary situations such as pandemics, natural disasters, and during the following periods to ensure readiness and planning. Efforts should be maintained to ensure free online



facilities that could be planned and accessed immediately or quickly even following the epidemic.

On the other hand, the review of the support services offered by the institutions demonstrated that these services varied between the institutions. For example, the issue of the effects of the delay in the evaluation of children with ASD on the parents is extremely important. Similar to all special need groups, early diagnosis is quite important in ASD. Medical examinations by pediatricians and pediatric neurologists (Baird et al., 2001), the primary care physicians who could provide early diagnosis, were interrupted during the pandemic, preventing educational evaluation in the institutions. The interruption in evaluation led to delays in early intervention. However, early intervention could improve the performance of the child, and these children adapt better to normal educational institutions. On the contrary, it was reported that the children could experience significant difficulties when the intervention is delayed (Kandasamy, 2018; Ünal & Pehlivantürk, 2004; Zwaigenbaum et al., 2015). Since early childhood interventions not only support the personal development of children but also include a process where several support services are provided to improve parental skills and promote the social participation of both parents and children, delaying the evaluation would not only postpone the initiation of the education, but also the therapy, health, social work, counseling services, etc. (Bakkaloğlu, 2020; WHO & UNICEF, 2012) Thus, children with ASD and their parents who cannot receive institutional intervention under the current conditions are expected to experience higher levels of stress (Altable et al., 2020). Therefore, providing information remotely to the parents is extremely important. It is necessary to develop remote evaluation remote methods that utilize advanced technologies in the future.

The institutions also differentiated on the issue of ASD and comorbid diagnoses and disorders. Obsessive-compulsive disorder, allergies, ADHD and asthma, and eating disorders could be observed as comorbid disorders. Literature review revealed that attention deficit and hyperactivity (Hendriksen & Vles, 2008; Simonoff et al., 2008), obsessive-compulsive disorder (Bejerot, 2007; Hendriksen & Vles, 2008), eating disorders (Dell'Osso et al., 2018; Huke et al., 2013) could be observed at a higher rate among individuals with ASD when compared to the general population. It was anticipated that the above-mentioned comorbid disorders could lead to further difficulties during the pandemic. Examples of these additional difficulties include the anxiety induced by the uncertainty about the duration of the pandemic, the empty shelves in the markets, the limitation of the access to desired brands by the availability of the inventory, or the provision of alternative products to the desired products. In a study conducted by Stankovic et al. (2020), it was reported that parents' anxiety levels increased when children with ASD insisted on eating the same food or were overselective. It was suggested that parents may require collaborative specialist support in these cases.

The parents were also often concerned about socialization (Gray, 2002; Havighurst et al., 2010). Since the individual socialization methods had to change in this process (Wright et al., 2020), it could be argued that it was more difficult for individuals with



ASD who already experience difficulties in social interaction and communication (Hattier & Matson, 2012; Lin et al., 2019). It was suggested that isolation during the pandemic could regress or falter certain previously acquired skills. This was among the biggest concerns of the parents (Stankovic et al., 2020). Thus, the fact that CARD planned virtual activities for individuals with ASD for distance socialization such as dramas, museum and park visits was significant, albeit insufficient. Therefore, it is important to focus on this spectrum-specific condition further.

Funding legislation and emergency public policies were rarely addressed. Certain institutions called for action. It could be suggested that emergency strategies should be implemented to amass resources such as social security and care services, insurance, food, and housing and make them available for individuals with ASD during the pandemic. The advocacy efforts of the institutions to address the increasing needs and diverse demands of individuals with ASD and their parents and to develop public services could accelerate the developments. For example, in Turkey, Autism Action Plan (AAP; 2016-2019) determined targets for the rights of individuals with ASD and their parents to improve their living conditions and identified the obligations of the related public institutions. It was considered necessary to design a new action plan for individuals with ASD after the pandemic.

The review of the employed support material and media demonstrated that institutions used visual stories, and especially social stories to assist children with ASD to understand coronavirus, prevention methods, routines, etc. In this context, the social stories authored by Carol Gray and charts were provided for the parents free of charge on several institution web sites. The institutions especially preferred these support materials since social stories are an auxiliary visual support facility developed to explain the social status of the individuals with ASD and assist them to exhibit adequate reactions (Gray & Garand, 1993; Sani-Bozkurt et al., 2017; Smith et al., 2020), and charts are effective on planning changes in routine and facilitate the transition from one activity to another (Banda & Grimmett, 2008; Flores et al., 2012), and both social stories and charts are evidence-based applications (NCAEP, 2020). In addition to providing social stories and charts as support material, an institution should also provide information about the implementation of these applications. Both applications have specific advantages, and these should be explained to the parents. In addition to the social stories and charts, all institutions provided videos with expert narratives or electronic texts for individuals with ASD and their parents. These resources both aim to inform and raise awareness. Furthermore, the organization of free webinars on various topics and social media posts improved the dissemination of knowledge. Especially, most institutions aimed to reach families using different methods by providing phone, e-mail, or live chat support to assist the problems experienced by families with adults or children with ASD. In a study, Stankovic et al. (2020) posed the question "How do you prefer to be informed about how to treat your child during a pandemic or an emergency?" and 43.5% of the parents preferred online assistance, while others preferred the school staff, healthcare professionals, child psychiatrist, or a pediatrician. Thus, it could be suggested that these preferences could be due to the fact that not



every family has the same level of access to information and communication technologies. Since technological facilities available for each household such as computers, network, mobile phones, tablets, income, education, age, etc. are different, their competencies and skills in using these technologies would differ as well (van Deursen & van Dijk, 2010; van Dijk, 2006). In addition to the use of technological tools such as computers, information could be shared on various mass media such as TV, which is available in most homes that do not have internet access. Legislation should be focused on the needs of individuals and families who are the members of the poorest class in the society and with severe ASD and limited opportunities (TİHEK, 2020).

Autism Awareness institution provided different support material and media when presenting information during the pandemic. The institution developed the same content as both an audioviusal file and electronic text. This flexible presentation where options were available could encourage the individuals with different preferences to access information. CARD, on the other hand, allowed the staff to share personal information on social media to reach families better and allowed the parents to collect information about the staff that would assist them. This facility could also show the parents that they were not alone in the process.

Autism Awareness institute provided animated stories and National Autistic Society provided cartoon chat and animations about coronavirus, especially for young children with ASD. Previous studies reported that animations facilitated learning of children with ASD (Ho et al., 2019; Holmgaard et al., 2013; Parette et al., 2011; Walsh & Barry, 2008). Child-friendly animations for the younger age groups would motivate children with ASD, support their imitation skills and contribute to their learning.

The review of the interinstitutional cooperation revealed that the uncertainties necessitated coordination between public institutions and non-governmental organizations to meet the increasing needs and diverse demands, educational needs of families with autistic members and individuals with ASD, improve their quality of life, ensure the sustenance of care services, and meet several other requirements. In this process, it was great to observe that the institutions reviewed in the study collaborated with health and education institutions as well as those that worked directly with individuals with ASD. This was considered important since it demonstrated that the institutions took the responsibility to meet the novel requirements and lend a hand to one another when necessary.

The review of the cooperation among Turkish institutions revealed that only Seed Autism Foundation collaborated with MNE. The collaboration between these two important institutions in Turkey could be considered a positive development, albeit insufficient. In fact, interinstitutional cooperation is the first among the six priorities determined in the AAP (2016-2019), which was developed to ensure equal utilization of the services provided for individuals with ASD and to facilitate their participation in all areas of social life independently. The action plan especially emphasized strengthening interinstitutional cooperation to ensure the continuity of medical,



educational, and support services (OEP, 2016). Thus, direct collaboration between the ASD institutions in Turkey, especially during times of emergency, is more important than ever.

It could be suggested that the emerging need for both educational and health support and the development of public policies improved collaboration among the individuals, society and institutions, and these efforts were good examples of solidarity, albeit limited. The analyses demonstrated that critical steps were taken to ensure the interaction and cooperation between experts in various disciplines employed by different institutions and organizations around the world and a common ground could be reached faster to cope with a similar pandemic or disaster in the future, which is a positive development.

In conclusion, the review of the work conducted by institutions all over the world demonstrated that the institutions responded rapidly to the needs during the pandemic. It should be noted that experts or institution proprietors who directly interacted with individuals with ASD developed various material and provided information free of charge. In this process, informative studies were often conducted, while practical work were mostly neglected. The efforts in Turkey were similarly informative services. It was observed that Seed Autism Foundation provided several services for individuals with ASD and their families such as social story material, free mobile applications in Apple Store and Google Play, resource documents, skill sets, support units, and webinars conducted on Zoom and Facebook during the pandemic. The work conducted by the Seed Autism Foundation in Turkey could be considered as an example for other institutions, while it was considered necessary to increase the number and diversity of examples through interinstitutional cooperation. Thus, ASD advocates and/or relevant institutions should analyze the current work on the reduction of the impact of the pandemic to create a more inclusive society in the long term, and to guide future studies.

It was considered necessary to indicate that there could be studies on the support services offered by the institutions reviewed in the present study for individuals with ASD and their families during COVID-19, the support material and media utilized by these institutions, and interinstitutional cooperation currently in development as this article was authored. Thus, the following recommendations are presented for future applications:

- In times of limited physical contact, data-protected user-friendly systems that do not rely on competencies and skills such as telehealth and telepsychiatry could be developed and employed by all age groups.
- Massive online databases that include quality material could be developed and made available for all.
- Online interaction-based applications and support services could be developed.



- Infrastructure and systems could be developed for distance family counseling and applied parent training.
- A distance educational evaluation and information/counseling system could be developed.

The following could be recommended for future studies:

- Longitudinal studies could be conducted to determine the long-term impact of the pandemic on the experiences/quality of life of children, adolescents, and adults with ASD and their families.
- Future studies could be conducted on the experiences of individuals with ASD and their families in distance education.
- Future studies could be planned to determine the assistance required by individuals with ASD and their families during the transition to the new normal.
- Empirical or mixed studies on the impact of the pandemic on the social skills of the children with ASD could be conducted.
- Applied research could be planned on the instruction of the physical and psychological prevention skills to individuals with ASD during the pandemic.



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