Journal of Global Awareness

Volume 2 | Number 1

Article 4

May 2021

Challenges for Children and Adolescents with Autism and Their Families during the Covid-19 Pandemic

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Recommended Citation

Pachner, Orsolya and Aranyi, Gabor (2021) "Challenges for Children and Adolescents with Autism and Their Families during the Covid-19 Pandemic," *Journal of Global Awareness*: Vol. 2: No. 1, Article 4. Available at: https://scholar.stjohns.edu/jga/vol2/iss1/4

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Abstract

The restrictions and lockdown measures implemented in response to the Covid-19 pandemic have posed a pronounced risk to the mental health of people with autism and their families. We discuss specific difficulties affecting children and adolescents with autism and their families during the pandemic, drawing on a broad range of recently published research in many countries and regions. A global perspective is adopted to provide an overview of the state of affairs and identify good practices. We consider challenges in four areas: research and practice related to autism, challenges facing children and adolescents with autism, specific difficulties in their education and care, and challenges facing their parents and families. Based on the reviewed work and our experience in group support sessions with parents of children with autism, we conclude that supporting families affected by autism should emphasize promoting the parents' well-being and coping potential to improve their resilience.

Keywords: autism, autism spectrum disorder (ASD), Covid-19, lockdown, mental health, telehealth, online support, parental stress

Introduction

The notion that the restrictions and lockdown measures enacted as part of the response to the coronavirus (Covid-19) pandemic should affect people's mental health and well-being seems self-evident. These everyday experiences have been the focus of a growing body of academic work, with a special focus on assessing the mental health of various risk groups, including children and adolescents (Singh et al. 2020), people with developmental and intellectual disabilities, and those with autism spectrum disorder (ASD) (Mumbardó-Adam, Barnet-López & Balboni, 2021).

The majority of such studies assessed people's mental health during the spring of 2020, amidst the strictest lockdown measures implemented in response to the pandemic. There was a particular surge in recently published cross-sectional research originating in China (Marques de Miranda et al., 2020). Studies addressing various age groups have identified an elevated prevalence of anxiety, depression, and post-traumatic symptoms. For example, surveys utilizing large sample sizes

have reported a prevalence of depression symptoms in children from 11.8% to 43.7%, increasing with age. Symptoms of anxiety followed a similar trend, between 18.9% and 37.4% (Marques de Miranda et al., 2020). The severity of the situation becomes especially apparent when these numbers are contrasted with the findings of a meta-analysis conducted in 2019, which reported a prevalence rate between 2.6% and 11.3% of depression symptoms in studies involving non-traumatized children, and 24.2% in traumatized children (Vibhakar et al., 2019). This comparison suggests that the occurrence of anxiety and depression in certain age groups during the pandemic have even surpassed that in traumatized pre-pandemic populations.

Certain factors affecting mental health related to the pandemic have been with us globally for over a year at the time of writing. Among these, some factors exert their influence during limited time periods and thus cannot be entirely attributed to the pandemic. While initial lockdown measures were lifted in most places after a few weeks, other measures and regulations related to the pandemic response remain pervasive. Still, lockdown remained constantly at the fore since specific groups, such as local communities, families, schools, and classes, faced periods of restrictions, even quarantine.

Among the effects of the pandemic, de Figueiredo and colleagues (2021) have emphasized those of social isolation and its biopsychosocial consequences to the development of children and adolescents. In addition to its direct effect on psychological well-being, social isolation acts as a stressor, thereby influencing the neuroendocrine-immune system through the mechanism of a chronic stress response. Another study by O'Sullivan and colleagues (2021) applied qualitative methods to describe the experiences of Irish families, where parents attributed the elevated levels of perceived stress, anxiety, and depression observed in their children primarily to social isolation.

A primary contributor to this isolation is school closures, the effects of which on the mental health of children and adolescents have received specific attention (Wang et al., 2020). School closures may contribute to mental health issues via difficulties in adapting to changes in the educational environment, as well as through a decrease in physical activity and social interactions (Marques de Miranda et al., 2020; Singh et al., 2020). A significant increase in time spent in front of

screens and its presumed effects on children's development is also worthy of mention (Wong et al., 2020; Hartshorne et al., 2021).

Review papers concentrating on the mental health of children and adolescents often dedicate distinguished attention to children and students with special educational needs. In cases associated with adjustment issues, including autism, there is an elevated risk of mental disorders and behavior problems. Indeed, children with autism are identified as risk groups in such reviews (Marques de Miranda et al., 2020; Singh et al., 2020).

Our primary aim here is to identify and discuss the specific difficulties affecting children with autism and their families during the pandemic, which poses a potentially greater risk to them compared to typically developing children. Alongside the disadvantages, we also point out a number of potentially positive aspects, such as good practices developed for dealing with particular, localized issues. We argue for the examination of these practices to generalize them for future situations.

Challenges to Autism Research During the Pandemic

Beyond its effects on everyday life, the Covid-19 pandemic influences many areas of research, including that of autism. Data is collected predominantly in online settings, while research that requires the physical presence of participants is mostly on hold. However, methods like Autism Diagnostic Observation Schedule (ADOS), which is used in the majority of studies for diagnosing autism, cannot be conducted online, while using masks in a personal setting may distort the results (Amaral & de Vries, 2020).

The pace of academic publishing has increased due to the pandemic in order to provide information support to face new challenges. Several studies have been published with the specific aim of advising professionals and parents on how to cope with various aspects of the pandemic (see Altable, 2020; Narzisi, 2020).

Perhaps the most generic challenge is related to how the pandemic influences research practice, which inevitably affects its focus as well. An example to note is research aimed specifically at investigating the effects of immune dysregulation and air pollution (Amaral & de Vries, 2020). Another key topic is the study of the mental health of people with autism and their families. To illustrate the magnitude

of interest in this area, a search in the Science Direct database for the keywords "autism" AND "mental health" (as of February 23, 2021) returned a markedly increasing trend (Figure 1).

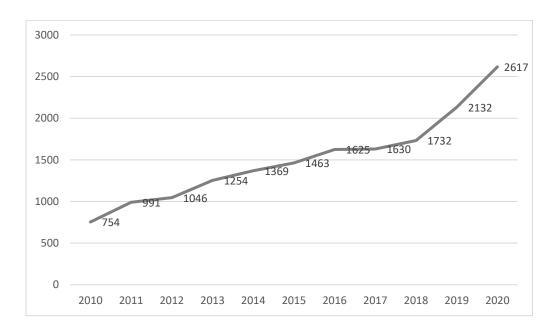


Figure 1. A number of articles returned for the keywords autism and mental health in the Science Direct database for the last ten years.

Challenges to Children and Adolescents with Autism During the Pandemic

The majority of specific challenges are due to the very nature of the symptoms that characterizes people with autism. There is evidence that people with ASD may be more prone to contracting the disease (de Sousa Lima, Barros & Aragão, 2020). While some point to physio-pathological mechanisms that are associated with autism, including the vulnerability of the immune system and differences in anti-inflammatory processes (de Sousa Lima, Barros & Aragão, 2020), others emphasize that comorbid conditions to autism and a high degree of severity increase the risk of infection by hindering the understanding of the pandemic situation and following hygiene rules (Mutluer, Doenyas, & Aslan Genc, 2020; Buonaguro & Bertelli, 2021).

Problems with understanding may be attributed to the communication difficulties associated with autism. However, adherence to the rules is not only hindered by a lack of understanding, but also by sensory sensitivity that may clash with the use of face masks, rubber gloves, or hand sanitizers. Accordingly, since December 2020 in Hungary, people with autism are exempt from having to wear a mask in public. At the same time, several civil organizations involved in autism support published guidelines to help parents of children with autism in familiarizing them with wearing a mask and in explaining to them the necessity for it. It appears that the mere public recognition of the problem had a positive influence on promoting the organization of aid and support.

As mentioned in the introduction, children with autism are also at an increased risk in terms of the mental health issues related to the pandemic and the subsequent lockdown measures (Marques de Miranda et al., 2020; Singh et al., 2020). For example, the so-called Covid-19 phobia has appeared among the many anxieties prevalent in people with autism (Sakamoto et al., 2020), which may be rooted in the difficulties of understanding the situation. There are also studies aiming at a general mental-health assessment of children with autism (see below). It is important to consider the time, place, and methods used when evaluating these studies. Although both autism and the pandemic are global phenomena, several factors may lead to differences in the findings. The majority of the studies have been conducted during the strictest lockdown period of spring 2020.

An Italian survey in April 2020 (Colizzi et al., 2020) found that the majority of parents (93.9%) described their situation as challenging and noted an increase in disruptive behaviors in their children. Another Italian study from the same period (Di Renzo et al., 2020) reported that 33.6% of parents experienced an increase of intensity in autism symptoms in their children, and found using repeated measures that several maladaptive behaviors increased in severity during the lockdown, such as hyperactivity, fear induced by new situations, and sleep regulation problems.

A Spanish study from the same period (Mumbardó-Adam, Barnet-López & Balboni, 2021) found that many parents deemed their children to have coped with the lockdown better than expected, and mentioned mostly positive changes in, for example, autonomy-related behaviors, being more communicative, and participating in family routines. Furthermore, the majority of parents rated the

emotional state of their children with autism as positive; only 23.4% reported that their child became more irritable.

It is important to note that Colizzi and colleagues (2020) used yes/no questions and Likert-type scales to collect answers from the parents, Di Renzo and colleagues (2020) applied standard instruments (ABAS-II, ASDBI, and SSP), while Mumbardó-Adam and colleagues (2021) used semi-structured online interviews.

Another aspect of note is the support the families received before and during the lockdown. Di Renzo and colleagues (2020) collected responses from the participants of an ongoing rehabilitation project (which allowed them to use repeated measures), who received weekly online psychological support during the lockdown. A similar rate of support was offered to parents participating in Mumbardó-Adam and colleagues (2021) study; 85.1% received psychological support before lockdown, while 76.6% continued to receive support during the lockdown. By comparison, in the study of Colizzi and colleagues (2020), which applied a substantially larger sample, the majority of parents (72.3%) reported not having had any contact with the local health services; moreover, 29.9% said to have received no direct support from the school, and only 56% of the families had at least weekly sessions with a private therapist.

An online survey in Turkey (Mutluer, Doenyas, & Aslan Genc, 2020) found a marked increase in behavioral problems in children with autism during the lockdown, including aggression, hypersensitivity, and sleeping and eating problems. They identified two factors influencing the mental health of children with autism: hindered access to special education and parental stress levels.

The study with the largest sample size during lockdown was conducted in the United States (White et al., 2021) using an online survey completed by 3502 caregivers of individuals with ASD. The majority reported disruptions in therapy during the pandemic. Those few that received support in a telehealth setting reported a low level of effectiveness. They found the most problems with children below five years of age, who were also most likely to miss out on telehealth support. A lack of support during the pandemic was identified as an additional source of stress for the families.

The studies conducted under the first wave of the pandemic that deal with mental health and autism, and especially those focusing on children with autism, point out

the importance of a particular symptom of autism: an adherence to routines, which exposes this group to the effects of changes and unpredictability to a greater degree than the general public (Narzisi, 2020; Altable, 2020).

During the 2020 spring lockdown, prominent advice was given to adults and families confined to their homes or a new structure for life activities. This was perhaps nothing new for most families affected by autism, as a key aspect of supporting children with autism is the development of daily routines and keeping to them. According to an Indian study (Daley, Weisner & Singhal, 2014), even 59% of adults with autism followed a structured daily routine related to higher functioning.

Behavioral inflexibility does not only manifest itself in the organization and completion of tasks on a daily basis. It may be even more challenging to face new, unexpected events. It seems plausible that the contracted social environment of homes during lockdown presented much less challenge and novel situations to children with autism, as opposed to everyday interactions in school or kindergarten. The situations most unexpected and most fraught with stress are exactly those of a social nature for people with autism, and not those arising from a departure from daily routine. This notion is tentatively supported by those studies that found an improvement in mental health during the lockdown, as opposed to its expected deterioration (Guidotti et al., 2020; Mumbardó-Adam, Barnet-López & Balboni, 2021).

Another aspect we wish to point out, albeit it received less attention in the aforementioned studies, is related to differences in social skills in autism. As it is difficult for people with autism to develop social connections, one might conjecture that they may not be so negatively affected by periods of lockdown with a contraction of social contacts. However, it is important to note that most people with autism need meaningful human relationships just like any other person. However, they are less adept at developing and maintaining relationships than their typically developing peers.

On the one hand, the loss of existing connections may constitute a major setback in the development of a child with autism, and social isolation is associated with a higher risk of developing mental disorders (de Figueiredo et al., 2021). On the other hand, those children and adolescents with autism who manage to maintain their social relationships online may even experience an improvement in their social life during this period. Many may find it easier to initiate online interactions (e.g., e-mail and chat) than in-person conversations, as they have more opportunities to think about others' messages and consider their reactions. Furthermore, the relationships most important for social skills are the ones that are maintained during lockdown with undiminished intensity; predominantly, the relationship with the parents.

Challenges in the Education of Children and Adolescents with Autism During the Pandemic

School closures during the pandemic have presented a major challenge for families in general, and for those with children or adolescents with autism in particular. The duration of closures and the level of institutions affected varied between countries and regions, depending on local conditions and policy.

The rapid transition to online-only forms of contact was fraught with difficulties for families and teachers alike, especially for parents of children with developmental disorders or disabilities. A survey conducted in the US (Jeste et al., 2020) estimated that approximately 30% of children with special needs were cut off from all therapeutic help and educational services during the lockdown in the US, estimating the figure outside the US at 50%. They found that 74% of children within the US (78% outside the US) were denied access to at least one type of service, while only 56% (32%) had access to tele-education. A large proportion of parents providing answers to the study (42.5% within the US and 45% outside) were bringing up a child with autism. Similarly, a Turkish study specifically aimed at families caring for children with autism (Mutluer, Doenyas, & Aslan Genc, 2020) found that access to special education during lockdown was completely suspended in 92% of the cases, while only 29% of children used video conferencing software.

Alongside surveys drawing large samples from various populations and groups, qualitative studies were also conducted to describe the situation. For example, a study in the UK (Canning & Robinson, 2020) concluded that expectations from the school and the workplace became mixed at home in both time and space during the lockdown, where previously the parents and their children could distance themselves from such pressures. A study conducted in Zimbabwe (Majoko & Dudu, 2020) on a small sample (n = 8) found that the entire family took part in the

home education of children with autism during the lockdown, each member according to their abilities and preferences. Instead of concentrating on academic tasks, many focused on activities for which there was no time or capacity before, such as cooking and cleaning.

From such studies, we postulate two main factors that mitigate the influence of school closures. One pertains to the extent to which access to education and services can be maintained or offered online; the other pertains to the ability of the parents and the family to cope with the changes. Both of these are, in turn, influenced by the child's abilities and the severity of their symptoms.

It is apparent in the cited studies that children with low-functioning autism (LFA) had a more difficult time coping with the changes; their parents reported more pronounced behavioral problems and were subsequently exposed to more stress themselves. In such families, home education can also be viewed as an additional burden and stressor. It may contribute to their disadvantaged situation that among the education services for children with autism, Applied Behavioral Analysis (ABA), social skill training methods, and physical therapies are among the most difficult to adapt to an online format. Children with better verbal abilities could access support more successfully online (Jeste et al., 2020).

In contrast to the above, many experienced a marked improvement in the mental health of children with autism. For example, Reicher (2020) pointed out that remote learning provided such an opportunity for many children with high-functioning autism (HFA) that they may consider keeping to it even after the pandemic. Children with HFA could better concentrate on learning in the absence of distractions and challenges they had to deal with in school, such as noises, smells, and the social environment. Many were actually released from the pressure of fitting in a community of neurotypical peers, which can demand a lot of energy from atypically developing children.

Studies show that compensatory strategies to promote integration are often associated with elevated anxiety resulting from unsuccessful attempts despite the efforts (Livingston, Shah & Happé, 2019). Homeschooling during lockdown may have eliminated this burden for many children with HFA.

Homeschooling is not entirely new to families affected by autism. Many decide for it on the grounds of higher expected education quality; however, such expectations

are not met in many cases. According to Simmons and Campbell (2019), parents often consider homeschooling their children with autism on grounds that school staff is unprepared and have little experience in dealing with autism. In cases the school can be an alienating environment where children with autism experience frequent bullying, which inevitably leads to a deterioration of mental health.

Parents' feelings of self-efficacy are boosted when making decisions that positively affect their children's well-being. Additionally, a decrease in stress within the family is positively reinforcing for the parents (O'Hagan, Bond & Hebron, 2021). This is reflected in the case of parents who noted a favorable change in their children during the situation imposed by the lockdown. It is indeed the mental health of the parents and the personalized learning implemented in the home environment that influenced the mental health of children the most (O'Hagan, Bond & Hebron, 2021; Mumbardó-Adam, Barnet-López & Balboni, 2021).

Alongside its advantages, home education also poses a number of difficulties and additional burden to families, especially for the parent who stays at home, but a decrease in income also influences the life of the family (O'Hagan, Bond & Hebron, 2021). Professional advice on home education before the pandemic was very similar to those implemented during the pandemic to support families affected by autism, including advice related to developing schedules, reinforce learning, integrate social development into the home environment, and formulating rules and keeping to them. In summary, the goal is to form a well-structured environment tailored to the individual (Mendoza, McKeithan & Griswold, 2019).

Challenges to Parents of Children and Adolescents with Autism During the Pandemic

Parents of children and adolescents with autism faced special challenges even before the pandemic. Studies found that the quality of life of parents with autistic children is at a deficit not only when compared to parents of typically developing children but to those who have children with other developmental disorders under their care (Eapen & Guan, 2016; Vasilopoulou & Nisbet, 2016). Alongside the severity of autistic symptoms and other characteristics of the child, parental characteristics and coping strategies also play a key role (Ekas, Pruitt & McKay, 2016), as well as numerous environmental factors such as emotional, physical, social, or economic distress. One of the most prominent sources of negative

environmental stress is a lack of social support network (Matthews et al., 2011). It is perhaps due to this that the involvement of families in general and the parents, in particular, has such a crucial role in the development of people with autism.

Solomon and Chung (2012) describe areas of autism support with the metaphor of a three-legged stool. The first leg corresponds to traditional therapeutic approaches (e.g., autism-specific testing and applied behavior analysis (ABA)), the second to alternative therapies (e.g., speech improvement, equine-assisted therapy, biomedical interventions, etc.), while the third leg corresponds to the emotional support of the entire family. It is noteworthy that, according to the authors, support in all three areas is necessary in order to achieve effective development.

The pandemic introduced an additional source of strain to parents of children with autism. On the one hand, just like everybody else, they had to face challenges such as working from home, increased occupational insecurity, or organizing daycare for their children. In addition to this, medical care for their children, in case taken ill, may require special preparedness from healthcare staff – just like before the pandemic. Such special treatment may not be available in every Covid ward (Nollace et al., 2020). On the other hand, negative changes in the condition of children with autism constituted an additional stress factor that parents of typically developing children did not have to face. The severity of autism in itself influences the level of stress experienced by the parents (Alhuzimi, 2021); however, this may also be interpreted as a reciprocal process wherein the stress experienced by the parents affects the mental health of the child. According to an Israeli study (Latzer, Leitner & Karnieli-Miller, 2021), the parents' coping effectiveness with the challenges of the pandemic was the most important determinant of the behavior and mental status of their children with autism. Those parents who were able to adapt to their children's needs even reported an improvement in their children during the lockdown.

Many forms of therapy and support were interrupted or suspended during the pandemic, pushing the role of parents to the fore in the development of their children with autism and thereby increasing the strain on them (Eshraghi et al., 2020). The significance of this development is underlined by a study that demonstrated the positive effects of medical- and neighborhood support not only on the mental health of parents of children with autism but also on the functioning of the children themselves (Hsiao, 2016). A study conducted in Saudi Arabia

(Alhuzimi, 2021) found that the frequency of professional support accounted for 10.3% of the variability in parents' mental well-being during the pandemic. During the lockdown and in many countries since then too, children with autism could only access professional help in the form of telehealth services, their personal interactions being restricted to their parents in most cases. This posed a new challenge to both the children and their parents, especially considering that evidence-based methods were not developed for a 24-hour setting (Degli Espinosa et al., 2020).

An interview study with parent-sibling dyads (Critchley et al., 2021) found that families of people with autism (predominantly adolescents and young adults) expressed a need for support services for family members. Specifically, they emphasized a need for guidance in supporting their family members with autism in unpredictable, uncertain situations such as the pandemic.

An attempt to bridge this gap was made by Italian ABA therapists, who adopted the ABA protocol to the specific needs of the lockdown (Degli Espinosa et al., 2020), in essence developing a dynamic and holistic method to provide guidance to parents. The protocol included a risk-assessment containing several stress factors (e.g., single parent, working from home, age of the child, etc.), and also evaluated the verbal skills of the child with autism, as this strongly affected the methods to be applied. The main points of intervention were structuring the day, choosing contextually appropriate activities, and using reinforcement systems.

An autism-specific training program was adapted to an online format even before the COVID-19 pandemic (Pennefather et al., 2018). As well as conveying the basic principles of ABA, the protocol contained mindfulness-based Acceptance and Commitment Training. The authors found that their three-week online program decreased parental stress levels and enhanced their knowledge, increased prosocial behavior in children, and decreased hyperactivity.

Therefore, it is important that parents' support should not be exhausted by information provision and advice; protecting their mental health and reinforcing their resilience is just as important.

During the 2020 spring lockdown, we implemented a support group for parents of children with autism in Hungary. Our goal was to provide emotional support to the parents, and to help them in identifying and harnessing their own resources.

Questions related to the development and support of their children with autism were specifically out of focus, which we found to be always strange for parents at first. However, they also tended to quickly recognize the importance of dedicating time to themselves in order to support their own mental health. The last two sessions took place online due to escalating lockdown measures. The parents emphasized the importance of the regularity of support sessions and the flexibility of an organization to meet rapidly changing circumstances, such as switching to shorter sessions with higher frequency, timed in accordance with the newly developing home-based routines.

Naturally, the children themselves came up during the discussions about adapting to the new circumstances; however, it was crucial that by attending the sessions, the parents were forced to carve out some me-time that they otherwise tended to sacrifice. Another positive result was that several parents started to seek each other's company outside the group. By the end of the group sessions, several parents noted a marked improvement in their children's behavior and functioning during the lockdown period. We expect that those parents who experienced an improvement in their children during lockdown had also increased feelings of self-efficacy, which in turn promoted their mental health and well-being.

Conclusions

Drawing on recently published work, we discussed specific challenges brought about by the Covid-19 pandemic facing children and adolescents with autism, their families, and practitioners in care and research. A summary of these challenges, and a tentative list of goals and areas of focus as discussed throughout the present paper, are presented in Table 1.

Table 1A Summary of Challenges Related to Autism During the Pandemic.

Area	Challenges	Goals and Areas of Focus
Research	Problems with online diagnosis	New research foci
	Changes in research focus and design	Online methods

		A closer link between research and support work
Children with ASD	Vulnerability to Covid-19 infection	Training of health professionals
	Vulnerability to mental disorders	Tools/guidance to explain pandemic and hygiene rules
	Loss in therapeutic services	Online support
	Difficulty in understanding the pandemic situation	Structure daily activities
	Difficulty in compliance with hygiene rules Effects of contraction of	
Education	social environment Loss of education services	Tele-education
Education	Loss of education services	Tele-education
	Lack of adaptation of online curriculum	Focus on life skills
	Challenges in homeschooling	Homeschooling and remote learning
	Blurring rules for school and home	Personalized education
Parents of children with ASD	Deficit in well-being (before and during the pandemic)	Focus on coping and resilience
With Tigb	Lack of social support network	Parent groups
	Increased load due to a deficit in support services	Online support services

A major problem for research and practice is related to difficulties in online diagnosis. The standard tool for autism diagnosis (ADOS) is difficult to adapt to an online setting. Many researchers use clinical diagnoses to forego the problem. However, it seems inevitable that the pandemic should affect how research is conducted, from the types of questions being asked to how data are collected and

analyzed. The pandemic steered academic work on autism into a direction that provides an opportunity to close the gap between research and practice.

Regarding the challenges that pertain to children and adolescents with autism, it appears that they are more at risk for contracting Covid-19 (de Sousa Lima, Barros & Aragão, 2020) and are also more vulnerable to mental disorders due to lockdown (Marques de Miranda et al., 2020; Singh et al., 2020). The symptoms of autism make it difficult for many of them to make sense of the pandemic situation, and understand and follow the plethora of rules associated with it. People with autism require special attention during lockdown since, for them, disruption of routines that affect us all is especially stressful.

Instead of an increase in support, the studies we reviewed reported a marked decrease in the provision of services during the pandemic, such as access to therapy and suitable education. We also found that those who received support from their schools were affected less by depression and anxiety. During school closure, many children with autism could only rely on their parents, who themselves were exposed to an increased degree of stress when compared to those with typically developing children. Parents with autistic children were characterized with a comparatively lower quality of life even before the pandemic, proportionate to the severity of autism symptoms in their children.

Most studies reported a decrease in the functioning of autistic children during the pandemic, despite some cases to the opposite, which resulted in increased stress for their parents. Promoting the mental health of parents is important in itself, but also because their role in the development of their children has become increasingly pronounced with the decrease in access to services.

We conclude that supporting families of children and adolescents with autism during the pandemic should focus on promoting the parents' coping potential and well-being, and improving their resilience. In addition to collecting good practice from the available literature, we presented our experiences where supporting parents have also led to positive changes in the condition of their children with autism. We believe such positive experiences may promote an increase in feelings of self-efficacy in parents. At the same time, we call for research into the effectiveness of various forms of online support, especially those targeting the parents.

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