Psychosocial and Behavioural Effects of the COVID-19 Pandemic on Children with Autism and their Families: A Systematic Review and Initial Data from a Multinational Online Survey

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Abstract

Background: Since COVID-19 has become pandemic, everyday life has seen dramatic changes affecting individuals, families, and children with and without autism. These entail, among other things, more time at home, digital forms of communication, school closures, and reduced support and intervention. **Aim:** Here we aim to systematically assess the effects of the pandemic on autistic and neurotypical (NT) children, and pursue a pre-registered hypothesis suggested by initial observations that some children with autism might respond comparatively well to a situation of constrained, predictable, and digital social communication during the pandemic. **Methods:** We provide a systematic review of current relevant work, including 76 papers selected from a database search until February 1, 2021. We then report survey data from several countries assessing activities, well-being (PedsQLTM), and social life in families with autism, and their respective change at various stages of the pandemic. We focus on differences between children with and without autism from within the same families, and on different outcomes for children with high- or low-functioning autism. **Results:** While children with autism scored lower in emotional and social functioning than their NT siblings, comparable decreases in well-being and increases in anxiety were seen for both groups, compared to before the pandemic. By contrast, decreases in adaptability were significantly more pronounced in autistic than NT children. Preliminary results suggest that changes were comparable for children with high- and low-functional autism overall, but individual differences prevail. **Conclusions:** Overall, although individual families do report some positive effects of pandemic restrictions, our data give no clear evidence that these generalize across children with autism, or even just to children with high-functioning autism. We discuss significant challenges for children with and without autism that need to be addressed to protect childrens' well-being under pandemic conditions but also point to potential in the present situation that could be used towards social participation and success in older children and young adults with autism.

Key Words: COVID-19; Autism; Systematic Review; Children; Online Survey; Quality of Life

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Running Title: COVID-19 Effects on Children with Autism

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Introduction

Across the globe, the COVID-19 pandemic has caused a state of crisis, in which local policymakers face the challenge of keeping infection numbers under control, while minimizing negative side effects on mental health and economic prosperity. For children and adolescents with autism^[1] and other developmental conditions, many support and intervention programs have either disappeared, or have been restructured to video-based offers that meet the requirements of social distancing. In this paper, we focus on current knowledge regarding the effects of the pandemic on children with autism and their families. In the past 12 months, new scientific papers on this issue have been published at a remarkable pace. Unsurprisingly, not all of these include new data. Several contributions aimed at providing useful tips directed at parents and caregivers of children that consider specific characteristics of autism^[2].

One impressive editorial perspective Jepsen *et al*^[3] discussed a survey of more than 60,000 clinical notes on case records from Denmark collected during February and March 2020, as a first step to identify pandemic-related psychopathology in children. The authors hypothesized that children with autism could be particularly vulnerable to distress related to the loss of daily routines, but were careful to explicitly note that their report could be biased in the sense that it focused on pandemic-related psychopathology, whereas the number of individuals that may have actually improved because of pandemic changes was unknown. Keeping in mind limitations of current research in the area, we here (1) provide a systematic review on the current state of knowledge regarding pandemic effects on autistic children and their families, (2) report on a pre-registered study hypothesis that pandemic effects on rated changes in anxiety levels, emotional and functioning, well-being, and coping of school-age children with clinical autism might also be more favourable when compared to neurotypical children (ideally their siblings), which we pursued in an online parent survey conducted in four languages between July and October 2020, and (3) discuss these results and their practical implications, before identifying current gaps in research and future perspectives.

Systematic Review

On February 1, 2021, we conducted a search on Web of Science, using the search terms “((Covid OR Corona) AND (ASD OR autis*))”, for the publication years “2020 OR 2021”. We initially identified 107 papers, which were then checked and of which 31 were excluded for

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various reasons (cf. Figure 1 for more details), leaving 76 papers for our systematic review. In an initial step, we categorized papers into one or more of the seven topics we discuss below, all of which were found to be covered by several papers. We then grouped papers into three types of paper, referring to quantitative studies, qualitative studies, or editorials/topical reviews/opinion papers. Of the 76 included papers, 26 were categorized as quantitative studies (cf. Table 1), 8 were categorized as qualitative studies (which could include case reports), and 42 were categorized as opinion papers, topical reviews or editorials. Note that we adopted a rather liberal criterion for categorizing a study as “quantitative”, when the study methods were described in some detail, even when only descriptive data (e.g., percentages) were reported. When discussing the surveyed papers, we occasionally refer to studies published before 2020 that are not related to the current pandemic but can be helpful to understand the methods, results, or interpretation of a new study.

Figure 1. Flow chart displaying the search and inclusion process, according to PRISMA group recommendations.

Table 1. Quantitative Studies Surveyed

Primary topic	Reference	Sample	Country / Time range of collection	Results
1 regional-temporal	Jeste et al. ⁷	N = 818 caregivers (N = 669 in USA, N = 149 outside USA)	USA / 15 th April – 4 th May 2020	74% children within the USA (78% outside the USA) received no longer at least one therapy/ educational service, 70% in the USA (58% outside) reported need to visit a healthcare provider
1 regional-temporal	Nonweiler et al. ⁶	N = 371 people with neurodevelopmental disorders	UK / 2 nd April – 2 nd June 2020	High prevalence of emotional difficulties, higher conduct problems, lower prosocial behaviours (compared pre-COVID-19 cohort)
1 regional-temporal	Samadi et al. ¹⁰	N = 336 caregivers of children with ASD; N = 30 daycare centers	Iran / n.a.	Hybrid model of telepractice supervised by daycare centers as useful, positive (61%) support in a low resource country
1 regional-temporal	Alhuzimi ⁹	N = 150 parents of children with ASD	Saudi Arabia/ 15 th June – 30 th June 2020	No or limited support for children with ASD available during lockdown: higher stress, lower emotional well-being for parents
Other studies which are listed under a different primary topic or do not report on quantitative data, but are also relevant for Topic 1: Chen et al. ²¹ , Ren et al. ²⁰ , Majoko & Dudu ¹³ , Sivaraman et al. ⁴⁰ , Summers et al. ⁴⁷				
2 well-being	White et al. ³⁰	N = 3502 caregivers (SPARK cohort)	USA/ 20 th March – 30 th April 2020	Many disruptions in support services (special education, speech/ language therapy, physical/ occupational therapies) during beginning of pandemic; low benefits for online/ telehealth services; no difference between age groups; stressor for families and deterioration of symptoms/ skill loss/ stagnation; increased distress and higher risk for crises
2 well-being	Ren et al. ²⁰	N = 1451 parents of special needs children (31% ASD)	China/ 18 th February – 22 nd February 2020	Mental and behavioral problems of parents as predictors of parents' state anxiety; stress as an predictor of parental anxiety during pandemic;

Table 1. Continued

2 well-being	Chen et al. ²¹	<i>N</i> = 1450 parents of special needs children (31% ASD)	China/ 18 th February – 22 nd February 2020	<p>parents social support as protective factor for parenting stress/ anxiety</p> <p>More mental health problems by parents of children with ASD than with a visual/ hearing impairment or intellectual disabilities; behavioral problems and restrictive behaviors in children with autism which are related to parenting pressure</p>
2 well-being	Colizzi et al. ¹⁹	<i>N</i> = 527 parents and caregivers of children with ASD	Italy/ 6 th April – 20 th April 2020	<p>Support from local healthcare service, direct/ indirect school support, private therapist; increased difficulties in building routines and leisure time; Children with preexisting behavior problems were more likely to show more intense and frequent behavior problems during pandemic</p> <p>High levels of stress (isolation, illness, finance) and disruption in life; greater degree when individual with ASD is younger; more severe symptoms followed by higher reported degrees of stress by the caregiver; greater levels of stress for individuals who had services before</p> <p>Increased anxiety and fear during COVID-19 (more parents than children)</p>
2 well-being	Manning et al. ²²	<i>N</i> = 471 family members and caregivers of individuals with ASD	USA/ 36 th March – 4 th May 2020	<p>Change of behavior during school closure; higher levels of anxiety and lower emotion management in children with ASD (against control group); change of routines as stressor, which predict higher levels of anxiety in the ASD group; higher levels of anxiety in caregivers</p>
2 well-being	Asbury et al. ²⁷	<i>N</i> = 241 parents/ caregivers of children with special educational needs and disabilities (82% ASD)	UK/ 22 nd March – 1 st April 2020	
2 well-being	Amorim et al. ²³	<i>N</i> = 99 parents of children with ASD and without	Portugal/ April 2020	

Table 1. Continued

2 well-being	Redquest et al. ²⁴	<i>N</i> = 91 siblings of individuals with intellectual/developmental disabilities	Canada/ April/May – July 2020	Siblings as important supporters (advantages of virtual programming for sibling), similar concerns for family caregivers in general, siblings prioritize own selfcare, no age differences to the reported concerns and emotions
2 well-being	Mutluer et al. ²⁸	<i>N</i> = 87 individuals with ASD	Turkey/ n.a.	ASD-related behavior increased, hours of sleep decreased, hypersensitivity increased during pandemic; behavior problems are a prediction for caregivers' anxiety; increased depression and anxiety symptoms in elementary school children; negative pandemic effect on childrens' psychological, social, and physical wellbeing
2 well-being	Neece et al. ²⁶	<i>N</i> = 77 (<i>N</i> = 48 with ASD) caregivers	USA/ 31 st March – 5 th May 2020	Challenges for parents during pandemic (being home, finance, lack of service); Positive aspects of being at home (being together as a family); positive coping strategies used through the pandemic (implement routines and schedules as most reported)
2 well-being	Alyoubi et al. ²⁵	<i>N</i> = 65 parents	Saudi Arabia/ June – September 2020	Problems in finding suitable advice from professionals; higher predisposition for anxiety and mental issues due to the social isolation
Other studies which are listed under a different primary topic or do not report on quantitative data, but are also relevant for Topic 2: Alhuzimi ⁹ , Jeste et al. ⁷ , Nonweiler et al. ⁶ , Saline ⁶³ , Türkoğlu et al. ⁷¹				
For Primary Topic 3 (schools, home schooling, home office, work opportunities), no studies were identified, but a number of other studies are also relevant for Topic 3: Jeste et al. ⁷ , Cahapay ¹² , Mutluer et al. ²⁸ , Asbury et al. ²⁷ , Courtenay et al. ¹⁷ , Newbutt et al. ¹⁸ , Reicher ³⁹ , Saline ⁶³				
4 leisure time	Kawabe et al. ³¹	<i>N</i> = 84 parents of children with ASD	Japan/ 30 th April – 8 th May 2020	Longer internet/ digital media use duration in ASD group before the pandemic, increased in both

Table 1. Continued

4 leisure time	Brondino et al. ³⁴	N = 18 individuals with ASD	Italy/ 19 th February – 4 th March 2020	groups during pandemic, increased digital media use time in control group, Importance of Physical activity for controlling problem behavior, among other physical activities as preventive countermeasures in reducing distress during COVID-19 restrictions
Other studies which are listed under a different primary topic or do not report on quantitative data, but are also relevant for Topic 4: Cahapay ¹² , Espinosa et al. ⁵ , Neece et al. ²⁶ , Mutluer et al. ²⁸ , Parenteau et al. ²⁹ , Colizzi et al. ¹⁹ , Narzisi ² , Kawabe et al. ³¹ , Saline ⁶⁴				
For Primary Topic 5 (moderating effects of additional intellectual disability and other developmental disorders), no studies were identified, but a number of other studies listed under a different topic are also relevant for Topic 5: Nonweiler et al. ⁶ , Chen et al. ²¹ , Ren et al. ²⁰ Brondino et al. ³⁴ , Wagner et al. ⁴⁵				
6 intervention	Wagner et al. ⁴⁵	N = 204 families with children between 16 – 36 month	USA/ n.a.	Tele-assessment tool for evaluation of ASD scores as predictor of diagnostic certainty; successful tool for ASD evaluation in the home setting; increased access for families in outlying areas; technology-related problems as key barriers for providers
6 intervention	Drozdowicz et al. ⁵³	N = 125 child/ adolescent psychiatrists	USA/ May – June 2020	Increased Sexual health skills/ attitudes/ knowledge after two weeks of training, also for a wide range of age/ language abilities/ developmental differences
6 intervention	Beaumont et al. ⁸	N = 70 child – parent dyads	Australia/ n.a.	Child increased improvements in social-emotional functioning, but no generalization of intervention effects to school environment possible (specific skill practice for school), decreased children anxiety levels from pre-intervention similar in the control condition, increased improvement in behavioral problems for intervention group

Table 1. Continued

6 intervention	Pollard et al. ⁶¹	N = 17 children and adults with ASD	USA/ n.a.	Successful transition from in-person ABA to telehealth services; heterogeneity of the group; effects for skill acquisition outcome
6 intervention	Yi and Dixon ⁵⁹	N = 13 families of a child with ASD	Canada/ February – March 2020	Telehealth parent training effective to increase parental adherence; benefits of a telehealth model in ABA services
6 intervention	Joseph et al. ⁵²	N = 3 college students (2 with ASD)	USA/ n.a.	Increased small talk abilities; lower off-topic conversational exchanges; reach similar level of conversation exchanges after intervention compared to normative data
Other studies which are listed under a different primary topic or do not report on quantitative data, but are also relevant for Topic 6: Samadi et al. ¹⁰ , Colizzi et al. ¹⁹ , Alyoubi et al. ²⁵ , Tohidast et al. ⁴² , Courtenay et al. ¹⁷ , White et al. ³⁰ , Kawabe et al. ¹¹ , Brondino et al. ³⁴ , Jepsen et al. ³				
7 perspectives	Warmate et al. ⁸²	N = 78 individuals with mental disabilities (13% ASD)	UK/ 22 nd July – August 2019	Little/No flexible working opportunities for people with mental disabilities, participants showed a positive/ adaptive willingness towards work; quiet/ safe work place as important for effective work
7 perspectives	Türkoglu et al. ⁷¹	N = 46 children with ASD	Turkey/ n.a.	increased chronotype scores (eveningness chronotype, sleep problems during home confinement), increase of autism symptoms; mediator effect of sleep problem level in the relationship between chronotype score and autism symptom severity, correlation between eveningness and greater neuroticism; positive correlation morningness and high conscientiousness/ agreeableness
7 perspectives	Nollace et al. ⁷³	N = 22 patients (N = 16 patients with autism)	France/ early March – mid April 2020	General COVID-19 signs (fever, fatigue, dyspnea, diarrhea) for COVID-19 patients with autism; atypical symptoms of patients with autism as

Table 1. Continued

idiosyncratic manifestations in the characteristic sensory context
Other studies which are listed under a different primary topic or do not report on quantitative data, but are also relevant for Topic 7: Wagner et al. ⁴⁵ , Cox et al. ⁵⁴

Regional and Temporal Factors

In different parts of the world, the temporal development of the pandemic and the respective responses by policymakers have been very different. Accordingly, it is important to keep in mind that empirical data need to be seen in this spatio-temporal context, so we listed this information in Table 1 when presenting studies with quantitative data. Pandemic effects on children are likely to differ considerably between a complete lockdown and effective confinement to one's own indoor living space for weeks (as was the case initially in Wuhan, China, and in Italy in early spring 2020), vs. a lighter version of lockdown in a region or phase with moderate infection numbers. As examples, initial quantitative evidence related to autism has quickly become available from China^[4], Italy^[5], the UK^[6], the USA^[7], Australia^[8], Saudi Arabia^[9], Iran^[10], or Japan^[11], and further qualitative research was reported from the Philippines^[12], Zimbabwe^[13], or Peru^[14]. Topics were diverse. For instance, a preliminary report from > 3000 families in China^[4] focused on caregivers' well-being and reported that 40-50% reported anxiety, depression, or stress during the first wave of the pandemic. An early paper from Italy^[5] reported on experiences with an initiative in which intervention for autistic children based on applied behaviour analysis (ABA) was almost instantly transferred and implemented by parents in the complete lockdown; parents were trained remotely via a telehealth system. Regarding country of origin, our survey reveals substantial numbers of contributions from the USA and the UK, whereas relevant reports from many countries (including Germany) and even world regions are currently missing (cf. Figure 2). With one partial exception^[7], there is currently a lack of studies that include data from more than one country or include a longitudinal analysis of pandemic effects at various pandemic phases. The interested reader is also directed to the contribution by Amaral *et al*^[83], which integrates a number of short comments and perspectives about the situation until June 2020, from editorial board members and global senior leaders of the International Society for Autism Research (INSAR).

Well-being of Parents, Caregivers, and Individuals with Autism

Difficulty in dealing with change is an important diagnostic criterion for autism spectrum disorders^[15]. So, it seems natural that the rapid changes brought about by the pandemic have prompted numerous authors to address the well-being of families with autistic family members. Theoretically discussing the topic, Bellomo *et al*^[16] pointed out the risks of delayed ASD diagnosis and comorbidities as well as reduced numbers and quality of therapy options. The

main concerns were globally poorer health outcomes in the future. Courtenay and Perera ^[17] and Newbutt *et al* ^[18] focussed on the limits of children with ASD understanding the changes and restrictions in daily activities, leading to mental stress, anxiety, and behavioural problems. Courtenay and Perera ^[17] also pointed out the increased likelihood of exploitation and domestic abuse, as children are no longer protected by their usual communities. Their key message was to make and keep services available, to improve quality of life and wellbeing.

Figure 2. Countries of origin of the 76 papers included in the systematic review (cf. Figure 1), colour-coded by the number of contributions on a World Map (<https://mapchart.net/world.html>, free online tool). In detail, contributions came from 19 countries, with information per country on the total number of papers/the n of quantitative studies/n qualitative studies, and n either topical reviews, editorials or opinion papers given in this order: Australia (1/1/0/0), Belgium (1/0/1/0), Canada (5/2/0/3), China (3/2/0/1), Denmark (1/0/0/1), France (4/1/0/3), Iran (2/1/0/1), Israel (1/0/0/1), Italy (7/2/1/3), Japan (2/1/0/1), the Philippines (1/0/1/0), Portugal (1/1/0/0), Saudi Arabia (2/2/0/0), Singapore (2/0/0/2), Turkey (5/2/1/2), UK (10/3/2/5), USA (29/8/1/19), and Zimbabwe (1/0/1/0). Note: Map data are for 79 papers, including 3 further papers (one from Peru, one from the USA, and one from Italy) which were excluded from the systematic review although they were topically relevant, either because they were written in a different language, or because we had no access to the full text.

The favoured empirical approaches to gain insight into family well-being were parent surveys and interviews. In their self-reports, the majority reported the phase of the first lockdown in Europe as a challenging period ^[19]. Parents described themselves as highly stressed ^[20, 21, 22] and impaired in their emotional well-being ^[9]. Compared to parents without autistic children,

caregivers of autistic children reported higher anxiety levels ^[23]. Factors like the younger age of children with ASD and higher severity of ASD were associated with greater parental stress ^[22]. When adult siblings served as caregivers for their siblings with intellectual disability, the majority also expressed worrying about the future, stress and guilt ^[24]. Alyoubi *et al* ^[25] also found a correlation between access to the appropriate help on the one hand, and less perceived guilt as well as more confidence of parents on the other hand. However, some positive aspects of the pandemic were also reported, including improved family relationships or being more present and peaceful^[26 see also 27].

For their affected children, parents reported changes in behaviour, poorer emotion regulation/management, and higher levels of anxiety, especially if routines were distorted, and compared to fewer ^[23] or less profound changes in the control group ^[6]. Further changes in behaviour included an increase in ASD core symptoms such as stereotypes ^[3], but also an increase in aggression, hypersensitivity, sleep and appetite alterations ^[28] and decreased social skills ^[29] or fewer prosocial behaviours ^[6].

To summarise, the concerns about the pandemic raised by practitioners and scientists are supported by the surveys conducted with affected families. As routines and help services were disrupted, the pandemic has put even more pressure on families with autistic family members, resulting in reduced well-being in autistic children and their caregivers ^[30]. This rise in stress and anxiety levels could lead to a general increase in mental disorders in the affected families.

Schools, Home Schooling, Home Office, and Work Opportunities

School closures and distance learning are a new global phenomenon resulting from the need to slow down virus spread. To meet the need for routines, experts advised affected families to maintain dedicated time slots for school work and to connect regularly with classmates and teachers ^[2,31]. Stennhoff *et al* ^[32] further developed detailed guidelines on how teachers and parents can support students' learning, e.g., by providing a well-structured learning environment and clear instructions.

In the course of the pandemic, about three-quarters of children initially lost at least one of their educational services, and about half of the children received at least one service through tele-education, as suggested by data obtained in April and May 2020 from the USA and beyond ^[7]. Tele-education was rated to be helpful to some extent by most parents. Those who received

more tele-education rated such services as more helpful. Parents wished for more frequent tele-education, a continuation of the previously provided services, and more in-person services. Qualitative research from Zimbabwe and the Philippines found that families needed to adjust their routines, implemented more diverse learning environments (e.g., educational games), but also gave some parents the opportunity to impose cultural gender roles in home education routines ^[12,13].

Leisure Time, Physical Activities, and Internet and Social Media Use

In many countries, recreational activities have been restricted as protective measures against the global pandemic spread. As children with ASD are more prone to being overweight and having a sedentary lifestyle, the restrictions and online learning environments likely added to these conditions ^[21]. Thus, detailed advice was provided to promote home-based physical activity ^[33]. Another line of advice also suggested structuring leisure time to some extent, e.g., by assigning different rooms for different activities, establishing rules for gaming and using the internet, or creating family playtimes ^[2, 31]

The difficulty of being at home all the time was indeed reported as the primary challenge by parents in the USA ^[26]. Implemented daily schedules, optimized for the child's needs, were reported as beneficial ^[29]. Parents had positive opinions on physical activities (e.g., health, social and psychological benefits), but barriers like having to work, security concerns, or insufficient online or tele-education (reported by parents as a lack in their own knowledge) made the implementation of physical activities difficult. In a study from Japan, internet use in children and adolescents increased during the pandemic throughout ^[11]. Although the control group had lower pre-pandemic internet or digital media use (median = 2 hours) than the ASD group (median = 3 hours), surprisingly, the increase was even more pronounced in the control than the ASD group (2 hours vs. 1.25 hours). Brondino *et al* ^[34] reported results for young adults with severe ASD treated in a daycare center in which all structures were maintained but adapted to the current situation (e.g., swimming and contact sports were substituted by daily trekking). Of relevance, these authors reported no significant aggravation of problematic behaviour, compared to pre-pandemic times.

Pandemic Effects on Individuals with Autism: Moderating Effects of Additional Intellectual Disability and Other Developmental Disorders

Several authors emphasize that pandemic disruptions of daily routines and predictability can be challenging for individuals with autism. Adverse effects could be particularly pronounced for children with intellectual disabilities, who might have difficulty understanding the context of these changes ^[35]. Conversely, it remains possible that some high-functioning children with autism could even respond positively to the reduction of direct face-to-face social interaction. In many ways, digital social communication and telehealth systems may promote a more predictable and controlled mode of interaction, thus resonating well with autistic individuals' tendency to "systemize," i.e., their drive to predict, control or construct systems ^[36]. This could explain why technology-based interventions may be promising for people with autism (for reviews, see Pennisi et al., 2016; Kowallik & Schweinberger, 2019; see also next section)^[37,38]. In school contexts, this is well illustrated by case reports of two boys with high-functional autism ^[39]. These boys enjoyed, and excelled in, distance learning. Reicher speculates that this may be because eliminating the demands of the "hidden curriculum" of subtle rules for classroom behaviour allows autistic children to use their cognitive and emotional resources for the formal curriculum, with positive effects both on performance and life quality. In the context of the pandemic, quantitative evidence regarding a modulating effect of intellectual functioning on the benefits of telehealth are largely missing, or indirect. White *et al* ^[30], in a large US dataset of 3502 parent surveys conducted between March 20 and April 29, 2020, discuss evaluations of telehealth offers by parents. One of their important findings was that reported benefits from online or telehealth offers increased with the age of the recipients, particularly for special education and mental health services, and were minimal for pre-school children.

Intervention

Telehealth

A need for healthcare support, in-home or center-based, was most commonly reported by parents during lockdown ^[19]. To understand the changes, comply, and stay safe, several interventions were presented to help autistic people comprehend the pandemic and precautionary measures. For example, this was realized through cartoons ^[31] and social stories that helped visualize more abstract facts. One intervention study aimed to make autistic children

comfortable wearing a mask by modeling and graduated exposure, descriptively increasing mask-wearing duration ^[40].

Periods of home-confinement have rapidly given rise to remote forms of healthcare interventions and trainings ^[41,42]. These shifts to telehealth offered unique advantages, like providing new insights into childrens' lives or greater flexibility in scheduling meetings. However, it also has disadvantages, like lacking traditional rapport-building activities and visualizations, distractions in the home-environment, or amplifying autistic communication difficulties ^[43]. Entirely telemedical approaches to monitor infants at risk for ASD ^[44], as well as online tools (TELE-ASD-PEDS)^[45] or complete working models for ASD diagnosis and intervention planning, were created ^[46,47]. A good implementation of those new workflows, including telehealth, could lead to better use of professional resources, improved access especially in rural areas, shorter waiting periods, and higher care quality ^[48,49]. Nevertheless, given the circumstances, even best-practice telehealth did not always reach the goal of improvement and left parents and care teams with open questions on how to proceed ^[50]. Loman *et al* ^[51] discuss in detail challenges and practical recommendations that are involved in both diagnosis and intervention in autism. Although the gold standard ADOS-2 cannot be administered validly in full without face-to-face interaction, these authors make useful recommendations for best practice under conditions of social distancing.

Beaumont *et al* ^[8] adapted an existing computer game-based social skills program for autistic children to a caregiver-supported version. This adaptation improved social skills and problem behaviour in the treatment group (N=35) compared to a control group (N=35) without training. A remote audio coaching for young adults with intellectual disabilities (N = 3) seemed to effectively teach small talk skills^[52].

Child and adolescent psychiatry practitioners in the USA were also targeted by an ASD-specific training on sexual health that consisted of video clips and video-conference meetings (like Zoom). This training significantly increased practitioners' skills, knowledge, and positive attitudes, while having a broad countrywide outreach ^[53].

Cognitive and Behavioural Methods

There has been an ethical discussion about ABA providers and the decision-making process for the needs of in-person treatments. Cox *et al* ^[54] argued that the risk of continued in-person treatment outweighs possible benefits for many clients and that temporal suspension of services

or telehealth may be the preferred option for most clients. Reviewing the scarce data base on telehealth, Schlietz and Wacker ^[55] suggested telehealth to be equally effective as in-person ABA. Others argued for maintaining 1:1 treatment as far as possible, and in-person treatments when needed ^[56] or even keeping the physical setting where possible ^[57] while implementing adequate safety procedures ^[58]. Yi and Dixon ^[59] provide details on implementations of their telehealth model for ABA, and Nicolson *et al* ^[60] added the clients' perspectives to the decision-making process by providing a caregiver interview to assess demand for changes in frequency or setting.

Espinosa *et al* ^[5] set up a very intense ABA-based telehealth intervention programme for parents, teaching them to implement daily structures, choosing appropriate activities and ABA-specific interventions (e.g., discrete trial teaching), setting up a reinforcement system. Pollard *et al* ^[61] showed that, given the right circumstances, telehealth can be as efficient as in-person treatment. Specifically, when the form of instruction (parent-instructed, telehealth parent-assisted, or telehealth directly with the practitioner) was chosen according to the child's abilities and the number of training hours was maintained, most children continued to benefit from ABA training.

Another line of suggested training is based on Acceptance and Commitment Therapy (ACT). For example, the detailed guidelines by Szabo *et al* ^[62] promote parents' use of schedules and routines, family values and norms, and positive reinforcement by suggesting specific values-based exercises. The 5 C's method (self-control, compassion, collaboration, consistency, celebration) for supporting families with alternative-learning children was also discussed in the light of the current pandemic ^[63]. Tarbox *et al* ^[64] fitted well-known ACT exercises to the pandemic situation to implement them into an ABA-based therapy framework to help children cope with the changes.

Kalvin *et al* ^[43] suggested modifications for a telehealth-based cognitive behavioural training for anxiety in children with ASD. They found specific changes in anxiety, depending on the type of anxiety (e.g. decreases in social anxiety, increases in fears of contamination or family safety) that made re-evaluations of goals and anxiety hierarchies and subsequently new exposure exercises necessary. They argued for letting parents provide developmentally appropriate information about COVID-19 while also setting realistic expectations with the children.

Overall, the new situation brought big challenges and a high risk of leaving a vulnerable population behind, while at the same time giving rise to the use of technology that might provide helpful additional resources in the post-pandemic world.

Brief summary of reviewed work

In the systematic review, we were able to survey substantial initial data collected across the globe and published within the first year of the pandemic. A large portion of the work was relevant to well-being and intervention, but data are also beginning to permit regional-temporal comparisons, and to inform about schooling or leisure time changes. We take away that children with autism tended to show less adequate emotion regulation and higher stress levels, particularly when daily routines were distorted. An increase in ASD core symptoms (i.e., stereotypical behaviours and decreased social skills) as well as an increase in aggression, hypersensitivity, sleep and appetite alterations were reported. Despite that, caregivers' well-being has been affected by anxiety, depression, or stress as routines and help services, schooling, and work opportunities were no longer available, or were available only in limited alternative forms. To meet the special routines required for individuals with ASDs, various studies made very clear that dedicated time slots for school/work and leisure time should be maintained given altered environments (e.g., more time at home, tele-education, educational games, physical activities at home, family playtimes, etc.). This was reported to buffer against increases in ASD core symptoms. Interestingly to note, benefits from online or telehealth offers appeared to increase with the recipients' age, particularly for special education and mental health services, and were low for pre-school children. Digital internet or media use seemed less increased in children and adolescents with ASD compared to control individuals, despite higher levels of pre-pandemic internet use. Many contributions related to diagnosis and intervention pointed out that the COVID-19 pandemic brings a high risk of leaving vulnerable individuals with ASD behind. At the same time, a huge push was observed in terms of telehealth implementations when it comes to explaining new hygiene practices using cartoons and social stories, tele-diagnostic instruments even for children under 36 months of age, telehealth set-ups for established cognitive and behavioural therapies (e.g., ABA and ACT) as well as social skills programs (e.g., Junior Detective Training Program). Positive aspects of the pandemic were sparsely reported but included improved family relationships or being more present and peaceful.

Online Survey

In our online parental survey, we focussed on assessing activities, well-being, and social life in families with autism, as well as changes at various stages of the pandemic. We aimed to compare pandemic effects on children with and without autism, ideally from within the same families. We collected data in summer 2020, after the first wave of infections in each country, when infection numbers were relatively low but respondents presumably had a relatively fresh representation of their experiences during the first wave. Initially, we had also planned to compare data across several countries and four languages to assess similarities and differences across different world regions. However, because our final sample was too small to permit comparisons across world regions with sufficient statistical power, we integrated the data across the four languages in the present report.

Our online survey (<https://aspredicted.org/us3py.pdf>) was preregistered on June 16, 2020. It was approved by the Ethics committee of the Ethical Commission of the Faculty of Social and Behavioural Sciences of the Friedrich Schiller University Jena (FSV 20/025). An initial power analysis using GPower 3.1 ^[65] suggested that a minimum sample size of 53 per group (autistic vs. neurotypical) would be required in order to identify a medium-size effect of $d = 0.5$ for a comparison between two groups (nonparametric Wilcoxon-Mann-Whitney t-test, one-tailed, alpha set to .05, power of .80). We stopped data collection after ten weeks, as infection rates in all countries of relevance at that time were significantly increasing, suggesting that the next infection-wave was coming (i.e., September 22, 2020, 7-day incidence per 100,000 inhabitants: Germany: 1,771; Iran: 3,120; Turkey: 1,672; UK: 4,189; according to interactive trashboard data from John Hopkins University, see <https://systems.jhu.edu/tracking-covid-19/>). We ended data collection with 70 surveys in total. For this reason, some of the analyses presented in the following may be based on low statistical power and should therefore be interpreted as exploratory, and with due caution. Nonetheless, in several aspects, they extend beyond what has been reported in the literature on ASD and COVID-19 so far, and thus are worthy of consideration.

Methods

Four parallel versions of an online survey were generated using SoSci Survey^[66] and made available to users via www.soscisurvey.de. The four versions differed only in the survey

language: English, German, Turkish and Persian (Farsi), each translated by a native/ fluent speaker of the respective language. The English version is provided in the supplemental material, and all four language versions are available via this link at osf.io/sm3ze/. The survey was online from July 16 to October 31, with the last dataset entered on September 22, 2020. During this time, 70 surveys were completed by parents of school-age children and adolescents with a clinical diagnosis of ASD in seven countries (German version, $n = 37$: Germany and Austria; Persian version, $n = 15$: Iran; Turkish version, $n = 13$: Turkey; English version, $n = 5$: Australia, USA, UK). Participants were recruited through professional networks and postings in social media.

A closer look at the data revealed that only 57 of the children and adolescents actually had a clear and confirmed clinical diagnosis of ASD. These children (14 female, 25%; 40 male, 70%, 3 undisclosed/diverse) varied considerably both in age (5-20 years, $M = 11.09$ years, $SD = 3.97$) and in level of required support (3 - very little, 26 - some, 21 - substantial, 7 - very substantial). For comparison purposes, parents were also asked to provide information on one neurotypical child they were in frequent contact with. This provided data for 53 neurotypical children (23 female, 43 %; 29 male, 55 %; 1 undisclosed/diverse; age 0-25 years, $M = 10.0$, $SD = 4.87$).

For a first set of analyses, the children and adolescents with autism were collapsed into a (comparatively) high-functional subgroup (requiring very little or some support; $n = 29$; AQ-10: $M = 7.21$, $SD = 2.21$) and a low-functional subgroup (requiring substantial or very substantial support; $n = 28$; AQ-10: $M = 8.11$, $SD = 1.47$).

Please note that not all parent reports contained full data for both one child with confirmed autism and a clearly neurotypical comparison child. A second set of analyses therefore focused on comparisons only within the 43 reports that comprised both one child with a confirmed autism diagnosis (AQ-10: $M = 7.65$, $SD = 1.91$; 12 female, 28 %; 30 male, 70%; 1 undisclosed/diverse, 2%; age: $M = 10.78$, $SD = 4.07$) and one control child that was indicated as uncontroversially neurotypical (AQ-10: $M = 1.67$, $SD = 1.84$; 20 female, 48 %; age: $M = 10.24$, $SD = 5.16$). A t-test confirmed that this novel form of familial reporting actually achieved a rather good age-match between the two groups ($t(40) = 0.862$, $p = .394$, $n = 41$ per group because age data were not provided for 2 children with and one child without autism, affecting age data for 2/43 pairs). We should add that in all analyses that compare autistic and neurotypical children,

we obtained similar results when using the entire dataset (thus having slightly larger samples at the expense of losing family matching).

Among other information (for a detailed description, please refer to the Supplemental Materials), the survey assessed demographic information about the responding parent, the children with and without autism, the rest of the family, and the child's autism diagnosis (using the *AQ-10 child version*)^[67]. We also asked about living conditions, local pandemic restrictions, and the parent's personal views on the pandemic. For both the child with autism and the neurotypical control child, parents indicated how much time per day they spent on a variety of activities (e.g., computer games, online learning, sleeping, and playing outside) before the pandemic, at the peak of the first wave, and at the time of answering (summer 2020, which was typically during low incidence rates). In addition, they reported on how well children complied with hygiene rules and filled in the *PedsQL™ General Well-Being Scale - Pediatric Quality of Life Inventory™ General Well-Being Scale* (PedsQL, Mapi Research Trust)^[68] in English, German, Turkish, or Farsi for Iran (contact information and permission to use for all four language versions: Mapi Research Trust, Lyon, France, <https://eprovide.mapi-trust.org>). Finally, parents were given the opportunity to mention specific problems, stressors, and support and to comment on the situation in general.

Results

We compared siblings with and without autism from the same families regarding scores on the *PedsQL™* dimensions *emotional functioning* and *social functioning*. These scores range from 0 to 100, with higher scores representing higher levels of functioning. Children with autism showed lower levels of both emotional functioning ($M = 49.3$, $SD = 19.6$, 10-95, $n = 43$) and social functioning ($M = 34.5$, $SD = 21.7$, range 0-85) than their siblings without autism (emotional: $M = 65.0$, $SD = 17.0$, range 25-100, $n = 43$; $t(42) = -4.702$, $p < .001$; social: $M = 76.5$, $SD = 23.13$, range 10-100; $t(42) = -9.638$, $p < .001$). Similarly, considering all children with autism, the high-functional children ($n = 29$) showed higher levels of emotional ($M = 57.24$, $SD = 19.67$; range 20-100) and social functioning ($M = 42.76$, $SD = 23.78$, range 10-100) than low-functional children ($n = 28$, emotional: $M = 45.89$, $SD = 19.1$, range 10-100; $t(55) = 2.209$, $p = .031$; social: $M = 29.11$, $SD = 20.82$, range 0-85; $t(54.5) = 2.308$, $p = .025$). In all groups of children, the range of responses was considerable.

Siblings with and without autism did not differ significantly in their reported response to, and compliance with, the hygiene recommendations regarding physical distancing, hand washing, and using disinfectant (all $ps > .3$), assessed on a 3-point scale from negative (-1) to positive (1). However, children with autism responded less positively to wearing a face mask ($M = 0.0$, $SD = 0.9$) than their neurotypical siblings ($M = 0.35$, $SD = 0.77$; $t(4239) = -2.303$, $p = .027$, $n = 43$). Considering all children with autism, low-functional children were reported to respond negatively to face masks ($M = -0.21$, $SD = 0.92$, $n = 28$), while the response of high-functional children was more positive ($M = 0.21$, $SD = 0.86$, $n = 29$; $t(55) = 1.788$, $p = .079$). Interestingly, all other means for hygiene behaviours were positive in all groups of children, suggesting that overall most children comply with hygiene recommendations most of the time.

At the time of the parents' reports, both autistic and neurotypical children showed a decrease in general well-being and social behaviour and increased overall anxiety compared to the time before the pandemic. These measures were assessed using a 5-point scale from *much increased* (2) to *much decreased* (-2). An overview is provided in Table 2, which first reveals changes for high- and low-functional children with autism, and second for autistic vs. neurotypical children from within the same families. Please note that comparisons with small sample sizes may be affected by low statistical power. Nevertheless, autistic children showed a much larger decrease ($M = -0.74$, $SD = 1.18$) than their neurotypical siblings ($M = -0.19$, $SD = 0.91$; $t(42) = -2.439$, $p = .019$; $n = 43$) in adaptation abilities. This pattern was numerically similar in the comparison within autistic children, potentially indicating greater declines in adaptation abilities for low-functional children than high-functional children.

Finally, we asked about changes compared to the time before the pandemic at the level of entire families with at least one child with autism ($n = 57$). This measure, which was constructed to score from -2 to 2, as above, revealed both negative and positive aspects of the pandemic: On the one hand, the general stress level ($M = 0.82$, $SD = 1.23$) and frequency of family conflicts ($M = 0.61$, $SD = 1.0$) were both reported to have increased considerably (simple t-tests against zero: $t(56) = 5.076$, $p < .001$, and $t(56) = 4.656$, $p < .001$, respectively). On the other hand, marked increases were also reported regarding the amount of time spent together ($M = 0.93$, $SD = 1.12$; $t(56) = 6.292$, $p < .001$) and emotional closeness ($M = 0.54$, $SD = 1.04$; $t(56) = 3.962$, $p < .001$). Again, parents used the entire scale from -2 to +2 to report on these aspects, suggesting a wide variability in how different families experienced and/or responded to the changes.

Table 2. Overview of mean changes in quality of life and function compared to the time before the pandemic (SD in brackets).

		General well- being	Adaptation abilities	Overall anxiety levels	Emotional reactions	Social behaviour
All autistic children with confirmed diagnosis	Low- functioning (<i>n</i> = 28)	-0.25 (1.14)	-0.93 (0.98)	+0.43 (1.0)	-0.14 (1.24)	-0.68 (1.28)
	High- functioning (<i>n</i> = 29)	-0.34 (1.08)	-0.59 (1.30)	+0.59 (0.87)	+0.10 (1.11)	-0.52 (1.15)
Independent t-tests		$t(55) = -0.322$, $p = .748$	$t(55) = 1.128$, $p = .265$	$t(55) = 0.636$, $p = .528$	$t(55) = 0.789$, $p = .434$	$t(55) = 0.50$, $p = .619$
Total (<i>n</i> = 57)		-0.30 (1.10)	-0.75 (1.15)	+0.51 (0.93)	-0.02 (1.17)	-0.60 (1.21)
Within-family reports	Autistic sibling (<i>n</i> = 43)	-0.40 (1.12)	-0.74 (1.18)	+0.44 (0.91)	-0.09 (1.23)	-0.58 (1.22)
	Neurotypical sibling (<i>n</i> = 43)	-0.44 (0.93)	-0.19 (0.91)	+0.47	+0.05 (1.0)	-0.26 (1.11)
Paired t-tests		$t(42) = 0.323$, $p = .743$	$t(42) = -2.439$, $p = .019$	$t(42) = -0.147$, $p = .884$	$t(42) = -0.650$, $p = .519$	$t(42) = -1.207$, $p = .234$

Note. The 5-point scale ranged from -2 to 2, so negative numbers indicate a decrease in the relevant function, positive numbers an increase. A paired t-test comparing children with ASD to neurotypical control children was significant regarding adaptation abilities. All other t-tests were not significant. Note that sample sizes are small and differ since comparisons between high- and low-functional autistic children show independent t-tests for all children with autism reported in the survey (*n* = 57), while comparisons between autistic and neurotypical children show paired t-tests for siblings within families (*n* = 43).

Brief Summary of the Online Survey Results

Our parent survey confirmed with the standardized *PedsQL*™ dimensions *emotional functioning* and *social functioning* that children with autism scored considerably lower than their control children who shared the same family environment and situation. On our change-based measures that focussed on different social and behavioural aspects (i.e., general well-being, coping/adaptation abilities, overall anxiety, emotional reactions, and social behaviours) before and at the peak of the pandemic, the extent of negative change was comparable for children with autism and neurotypical children, except for coping/adaptation abilities. The latter was noted as significantly stronger for children with autism compared with neurotypical children. Note, that our working hypothesis of better outcomes for individuals with autism was not confirmed on any of our measures. On a precautionary note, all our measures showed a wide spread of responses, indicating that some individuals and/or families struggled hugely under pandemic restrictions, while others coped quite well. Along those lines, some positive findings in this survey were that most children responded comparatively well to recommended hygiene behaviour, except that autistic children were hesitant about wearing face masks. Further, and similarly as reported in some papers from our systematic review, families spent more time together and experienced greater emotional closeness within the family.

Single-Case Reports from *Early Support and Counselling Center Jena, Germany*

In Jena, Germany, the *Early Support and Counselling Center* was forced by the local authorities to stop offering physical special needs services in kindergartens, schools, and homes in the affected families. The change was sudden, and many parents of children with autism reported that it elicited considerable stress and anxiety due to the loss of daily routines and insights from a third party. Here we report on two specific narrative experiences as reported to the early support and counselling service point Jena:

J., a 12-year-old boy with atypical autism visiting a special school, normally likes his school; his mother and caregivers report that he often engages in role-playing and enters his own imaginary world when feeling overwhelmed. During German school closures in Spring 2020, he played “school” all day long in his room. Although he did attend classwork, his mother reported that he is otherwise almost impossible to contact in his imaginary world. The situation improved during summer, but after the second school closure in late 2020, he typically refused to leave his

own room and refused to do classwork. When he was allowed back to childcare in his school in February 2021, he was jubilant to have his school back.

L., a 14-year-old boy with high-functional autism who usually likes going to high school where he regularly obtains very good to good grades, coped well with the first German lockdown in Spring 2020. Parents and caregivers reported that he developed a good structure, regularly submitted quality classwork from home to his teachers, and he generally enjoyed homeschooling very much. However, after schools re-opened in late Spring 2020, L. did not physically attend classes until the summer break, apparently because of his asthma as a risk condition. In the second German lockdown in November 2020, he coped even less well, found the school internet cloud to be poorly structured, and generally was overwhelmed by the multitude of tasks. L. did not ask his parents for help because he “was used to managing on his own” and did not confess that he had difficulties meeting demands until the teacher informed parents that he had stopped submitting classwork altogether.

On a positive note, the *Early Support and Counselling Center Jena, Germany*, reports that most adults with autism experienced the lockdown as less problematic and sometimes even as relaxing due to the reduction of face-to-face social contacts. Manyents also reported positive effects on their family life, which they attributed to more time spent on physical activities, such as hiking, play, or music.

Brief Summary of Single-Case Reports

Like those offered by the *Early Support and Counselling Center Jena, Germany*, support services were restricted by law. This loss posed an additional challenge to children with autism and their families, as third-party support was unable to intervene when an increase in ASD core symptoms was observed. It was reported that the younger the affected individuals, the more they struggled with the Covid-19-induced changes. Interestingly, family relationships were generally described as positively different, as more leisure time was spent together.

General Discussion

An efficient response to the challenges of the COVID-19 crisis requires a massive effort from the social and behavioural sciences^[69], to reveal more information on potentially devastating effects of the pandemic on vulnerable individuals, like those affected by autism. In the current paper, we provided a systematic review of qualitative and quantitative works on individuals and families

affected by autism during the global COVID-19 pandemic, considering publications from 2020 to February 1, 2021. Further, we provide results from a parent-survey of school-age children and adolescents with and without a clinical diagnosis of autism from within one family household, conducted from July 16 to September 22, 2020. We then provide examples of autism case-reports from the *Early Support and Counselling Center Jena, Germany*.

From our systematic review, it became clear that more cumulative research is needed both to quantify pandemic effects on autistic individuals requiring various levels of support, and to further develop, optimize, and evaluate support offers for schooling and telehealth interventions. At the same time, and unsurprisingly, there are still critical gaps in knowledge. To fill these blind spots, we anticipate that researchers' global effort will be needed to integrate data from across the world and different pandemic phases. In the studies we reviewed, we also identified topics that were covered only occasionally (sometimes only in one study). Some will be highlighted here as they cross the borders of social behavioural and medical sciences and are still very rare.

We anticipate and welcome further work towards a holistic approach that considers mental and physical characteristics of autistic individuals. For instance, in an editorial letter, Baghdadli *et al* ^[70] pointed out that autistic people with more severe intellectual disabilities may be particularly vulnerable due to their living situation, but also because they can have immune systems with increased levels of inflammatory cytokines, putting them at increased risk for severe forms of COVID-19. Another issue that has been considered in the study by Türkoğlu *et al* ^[71] was sleep problems of children with ASD during the COVID-19 pandemic, their relationship to symptom severity, and perspectives of reducing sleep problems to mitigate negative effects.

Special needs should be considered for people with autism who are hospitalized with COVID-19. Two papers from the same institute in Paris^[72,73] report initial experiences and quantitative data from a COVID unit for autistic patients only, created in an interdisciplinary collaboration between child and adolescent psychiatry and specialists for infectious diseases. The authors describe how this improved the response to both specific psychological and medical characteristics of patients with ASD (e.g., due to higher prevalence of gastrointestinal or immunological disorders). Amongst other measures, non-invasive methods when ventilation is needed should be considered more systematically in those approaches ^[74] in order to reduce anxiety and arousal. In parallel, better routines need to be developed and evaluated to meet the

need for home-based testing for COVID-19 infections in ASD in a way that considers sensory concerns and compliance of individuals with autism^[35].

For our parent-survey of school-age children and adolescents with and without a clinical diagnosis of autism we are acknowledging our analyses' limitations due to the comparatively small number of respondents. At the same time, we believe that they provide some useful and relevant insights for future research. As such, we recommend sampling autistic and non-autistic individuals from the same (family/care) environment where feasible, in order to make conclusions more autism-specific and less dependent on societal and cultural influences. Further, change-based measures comparing effects in more relaxed and more constrained pandemic times (e.g., trough vs. peak of a wave; summer vs. winter; soft vs. hard lockdown measures) also seem important in order to keep societal and cultural influences better controlled. On a more critical note, we point out that third-party reports from parents and primary-caregivers of affected individuals with autism may be biased more than, for instance, reports from support services, teachers, therapists or medical staff. Future policy-makers may want to consider that, while acknowledging that parent or primary-caregiver reports are valuable in their own right. For instance, they can give insights that more objective reports can never provide, by posing a social norm that individuals with autism tend to adhere to, and as such mask their autism characteristics^[75].

Finally, we would like to mention a few positive findings. Although the numbers are hard to interpret, it seems that most children responded comparatively well to recommended hygiene behaviour, with the exception that autistic children were hesitant about wearing face masks. When integrated with others' findings reviewed in this paper, and if this will be corroborated by further research, we believe the evidence that children with autism can adhere well to these recommendations when conveyed appropriately is encouraging. Also consistent with other findings ^[e.g., 25], the present data indicate two other positive aspects. Specifically, due to either advice or legislation to stay at home, families with children with autism spent more time together, and experienced greater emotional closeness within the family. Without a doubt, this could contribute to resilience in the face of profound challenges and to parents' and childrens' ability to deal with these difficulties - an aspect that is not always reflected in press reports.

Perspectives

The present work has made clear that more research, especially in hitherto neglected areas, is needed both to quantify pandemic effects on autistic individuals requiring various levels of support, and to further develop, optimize, and evaluate support offers for schooling and telehealth. Beyond that, it seems appropriate to reflect on challenges and changes the pandemic imposes on our societies in general, and on the impact these changes can have on neurotypical people and people with autism in the longer term.

When considering the psychological and neurobiological effects of social isolation, it is hardly surprising that the degree of isolation many humans experience during the COVID-19 pandemic is a likely threat for mental and bodily health. In a recent feature review in response to the pandemic, Bzdok and Dunbar ^[76] summarize the important role of social bonds for specific aspects of human health, and illustrate why some forms of digital communication cannot well compensate for real-time face-to-face interaction. When communicating, our brains are tuned to process multiple simultaneous signals from different senses, to use prosody and eye contact to steer a conversation or joint action, and to process dynamic representations of the face, the voice, bodily motion and other activities from a partner ^[77]. Recent research suggests that social interaction is a critical driving factor that shapes brains through the lifetime ^[78], and that has shaped the human brain during evolution ^[79]. Bzdok and Dunbar ^[76] consider several effective means to mitigate costs of isolation, such as supporting friendships, mental training towards empathy or perspective-taking of others' mental states, or joint singing. Although joint singing typically happens in choirs and singing groups, the internet has enabled musicians to perform together over distances via imitation and remix. We may be struck by the success of Scots' postman Nathan Evans, who in December 2020 became famous after posting the 19th-century shanty "The Wellerman". This example, and the overwhelmingly positive response of people suffering from social isolation, could point to a therapeutic form of social interaction via digital media that is not (much) compromised by their technological limitations. In this instance, it may help that familiar music is temporally predictable, making it easy to sing or play along, while eye contact is of little or no relevance.

It can be expected that people with autism suffer from social isolation too. Although certain behavioural signs in autism (such as low levels of eye contact) have long been taken as an indicator for their lack of social interest or motivation, this interpretation is likely incorrect.

Instead, autistic people just express their social motivation in unconventional manners^[80,81]. Mitchell *et al*^[81] emphasize how being misperceived, against the background of social conventions, creates risks for mental health and well-being of autistic people. The “double empathy problem” describes how autistic individuals find fitting into society difficult not only because they misunderstand others, but also because they are misunderstood by others - reflecting a bidirectional failure of empathy^[81]. In some sense, the COVID-19 pandemic has submitted humankind to a global experiment, in which established social conventions (e.g., handshaking, keeping distance according to one’s peripersonal comfort zone, preferring face-to-face communication) have been eroded or are changing dramatically, creating ruptures in social interaction for everyone. While we need to take the associated risks seriously, the current situation of changing social conventions could also provide potential and chances to promote a better and more humane understanding between autistic and neurotypical people in moments of crisis.

Finally, although this article focuses on children, changes relating to social distancing are affecting children and adults, and schools and employment. Regarding prospects for work opportunities in a difficult economy, one study from the UK^[82] assessed 78 individuals with mental handicaps, who reported that the most essential flexible working opportunity to help them work efficiently was a safe and quiet place to go when overwhelmed. Data for that study were actually collected in summer 2019, but the results were discussed in the context of the pandemic. The paper, published in an outlet in business and economy, gives an impressive account of how societies currently waste potential to empower adults with autism, and how this potential could be used for both integration and economic and financial success. As telework often seems to provide an optimal context for good performance, we believe the pandemic could provide a unique window of opportunity in several fields which will ultimately become important not only for children, but also for employers and many adults with autism.

Author Note

Author contributions: Design and discussion of the online survey: HK, DS, SSD, CD, AEK, SRS. Implementation of the online survey: DS, HK, with input from SSD, CD regarding different language versions. Data analysis and report of the online survey: HK, CD, all authors. Plan and evaluation of material for the systematic review: AEK, JR, SRS. Systematic review writing: AEK, SRS, all authors. Practitioner and caregivers viewpoints: GK, all authors. Supplemental Material: CD, all authors. We thank Franziska Kramer for her help with data processing (online survey).

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Supplementary Material 1

Detailed Description of the Questionnaire

This document contains supplemental material of the manuscript:

Kreysa, H., Schneider, D., Kowallik, A.E., Dastgheib, S.S., Doğdu, C., Kühn, G., Rutloff, J., & Schweinberger S.R. (2021). Psychosocial and Behavioral Effects of the Covid-19 Pandemic on Children with Autism and their Families: A Systematic Review and Initial Data from a Multinational Online Survey [Manuscript submitted for publication].

Online-survey was generated via SoSci Survey (Leiner., 2016) in English and translated into Turkish, German, and Persian (Farsi) by native speakers. Separate links were distributed for each language. Full version of the online questionnaire in English is attached in the Supplementary Material 2 section.

1) Greetings (Screen 1)

The questionnaire starts with greetings and a brief explanation about the aim of the study (e.g “... how the current pandemic has affected the daily life and well-being of families with children with autism in different countries.”).

2) Information for Participants (Screen 2)

Detailed information about the study was presented with a download link.

3) Declaration of Consent (Screen 3)

Participants were able to declare their consent by clicking the “next” button after they were informed in detail. This declaration included the conditions of voluntary participation and their right to end participation any time they would like. Participants were also informed that the personal data are collected in course of this scientific study under required ethical standards.

4) Code for Anonymity (Screen 4)

Participants created an anonymous code by using specific combinations of letters and digits of the participants personal information (undisclosed here).

5) Explanation for the Labels: Child A and Child B (Screen 5)

The labels of Child A (child with Autism) and Child B (one other child without a diagnosis who lives ideally in the same household) were explained with a paragraph:

*“ ...we will refer to this child with **Autism** as **Child A**. We will also ask you to fill out some questions about one other child (**Child B**) who ideally lives in the same household. If you do not have another child in your household please report about another child with whom you are in close contact. We will refer to this child as **Child B**. Child B should **not** have a clinical diagnosis on the Autism Spectrum. “*

6) Socio-demographic Information (Screen 6 / 7)

Participants were asked about the current information about themselves, their children, where they live, and how the pandemic has affected them. After the question of how many people mostly live in the household, participants filled out this part separately for themselves, Child A, Child B, another sibling, other parent, and another household member. Except for the age, the questions were in multiple-choice format with an - “other”- open answer option particularly for the profession:

- Age (in full years).
- Gender (female, male, other, prefer not to say).
- Profession (pupil/in school, training/apprenticeship, university student, employee- Full time, employee – Part-time, self-employed, unemployed/seeking employment, other).
- Diagnosis (“Is a clinical diagnosis on the Autism Spectrum known for this person?”; Yes/Suspected/No).

7) Diagnosis (Screen 8)

The severity and comorbidity were asked for Child A:

- “For Child A, please indicate the severity of impairment due to their Autism Spectrum Condition”; requires little or no support / requires support/ requires substantial support / requires substantial support)
- “Is Child A, impaired in any other way?”; yes (open option for further information)/ no, prefer not to say)

8) Autism Quotient – Short (Screen 9)

Participants filled the 4-point Likert child (parent report) version of the AQ-10 for Child A and Child B separately. Note that only the English version is validated (Allison et al., 2012). For the German, Turkish and Persian (Farsi) languages, the items were taken from the long versions of the AQ-Child.

9) Socio-Demographic Information – Micro (Screen 10)

Further information about the accommodation was asked with multiple choice questions with “other” open answer options.

- What kind of accommodation do you live in? Flat/house/other
- Do any household members live somewhere else some of the time? no/yes, please specify
- Does your accommodation have direct access to the outside?
Balcony/garden/yard/other, please specify
- How many bedrooms are there in your accommodation?
- Is there a private room for each child in the household? yes/no/unclear

10) Socio-Demographic Information – Macro (Screen 11)

Participants were asked to report the population size of their community under 6 categories from “less than one hundred” to “more than one million”. They reported the country they are currently living in and whether this country is the one that they were born.

11) Corona-Pandemic Restrictions (Screen 12)

First, they reported whether the pandemic leads to administrative restrictions of school closure and/or complete lockdown at any time. Then, they were asked whether these restrictions are currently still in place with 4-option multiple-choice (yes/no/partially/I don’t know) including limits on groups of people, limits on time and activities outside the house, wearing protective clothing/face masks in public, travel restrictions, limits on sports and cultural activities, restrictions for religious events, restricted (non-corona) health-care and therapy options, mandatory quarantine, other (e.g., requirement/encouragement to carry tracking devices, documentation of purpose of visit or health status, ...).

Finally, they reported their personal prediction about the time when the pandemic will be over (1 month / 3 months/ 6 months / 1 year / several years / never).

12) Report of the Activities and Time Budgeting for Child A and Child B (Screen 13 / 14)

Participants reported how much time Child A (i.e., the autistic person they are reporting about) spent/spends time on specific activities in a typical 24-hour day for three different time periods namely: “before corona restrictions”, “at the peak of the crisis” and “currently”. They were instructed to give proportions of the hour (e.g., 30 min=0.5) for the following activities:

1. Use of digital devices (smartphone, tablet, laptop) for social communication (e.g. chatting with friends and family).
2. Use of digital devices (smartphone, tablet, laptop) for entertainment (e.g., games, films, surfing the Web).
3. Use of digital devices (smartphone, tablet, laptop) for education (e.g., homeschooling).
4. Use of digital devices (smartphone, tablet, laptop) for -therapy, consultation, and coaching.
5. Special interests and hobbies
6. Inside the house
7. In the garden or on the balcony
8. Outside (but not in your own garden or on your own balcony)
9. Sleeping or in bed.

After that, participants were asked to answer the same questions for Child B (i.e., the other child/adolescent they are reporting about).

13) Health and Well-Being of Children/Adolescents (Screen 15/16)

In this part, participants rated the following aspects for Child A and Child B separately at present moment in time, compared to the time before the current pandemic (much decreased /slightly decreased/ similar/ slightly increased/ much increased):

- General well-being
- Adaptation abilities
- Overall anxiety levels
- Emotional reactions
- Social behavior

14) Responding to the Pandemic Hygiene Routines (Screen 17)

Participants indicated separately how Child A and Child B responds to the following pandemic hygiene routines (not applicable/ negative/ neutral/ positive):

- Maintaining physical distance from other people (1,5 m)
- Regular hand- washing
- Use of disinfectant

- Wearing a face mask

15) PedsQL – Pediatric Quality of Life Inventory (Screen 18-23)

Participants filled out the Version 4.0 – Parent Proxy Report for Children (ages 8-12) of Pediatric Quality of Life Inventory 8 separately Child A and Child B. (*PedsQL*, Mapi Research Trust; Varni et al., 2001). The questionnaire consists of a total amount of 23 Items on the four distinct dimensions (physical functioning, emotional functioning, social functioning, school functioning).

16) Effects on Entire Family (Screen 24)

Participants rated the following aspects for their family at the present moment in time, compared to the current pandemic (much decreased/ slightly decreased/ similar/ slightly increased/ much increased):

- Overall stress levels
- Regular daily structure
- Conflict
- Time spent together
- Emotional closeness

17) Support and Challenges (Screen 25/26)

In this part, participants indicated whether they receive any form of support through the following people or institutions:

- Close family
- Extended family and friends
- Neighbors
- Institutions
- Health service
- Government

After that, there were open-answer parts to ask which (if any) forms of support they find particularly useful and why. Then two additional questions in open-answer format were:

- (How) did the current pandemic affect your child's ASD-specific educational and therapy/ rehabilitation activities?
- Did you experience any other specific challenges during the current pandemic?

Finally, with an open-box, they were asked to give additional information about any other aspects of the pandemic that were important to them.

References (Supplementary Material 1)

Allison, C., Auyeung, B., & Baron-Cohen, S. (2012). Toward brief “red flags” for autism screening: the short autism spectrum quotient and the short quantitative checklist in 1,000 cases and 3,000 controls. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(2), 202-212. <https://doi.org/10.1016/j.jaac.2011.11.003>

Leiner, D. J. (2019). SoSci Survey (Version 3.2.21) [Computer software]. Available at <https://www.soscisurvey.de>

Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL™ 4.0: Reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Med Care*. 2001 Aug;39(8):800-12 <https://doi.org/10.1097/00005650-200108000-00006>

Supplementary Material 2

Online Questionnaire (English)

This document contains supplemental material of the manuscript:

Kreysa, H., Schneider, D., Kowallik, A.E., Dastgheib, S.S., Doğdu, C., Kühn, G., Rutloff, J., & Schweinberger S.R. (2021). Psychosocial and Behavioral Effects of the Covid-19 Pandemic on Children with Autism and their Families: A Systematic Review and Initial Data from a Multinational Online Survey [Manuscript submitted for publication].

Thank you very much for participating in our survey. The information you provide will help to provide insights into how the current pandemic has affected the daily life and well-being of families with children with autism in different countries.

GR01

Please note that you must first read through some ethical guidelines before the actual questionnaire begins.

Also note that there is no "Back" button. Therefore, please read each page carefully before proceeding to the next page and do not use the "Back" function in your Internet browser. Thank you very much.

GR02

Information for Participants

Study: "Effects of the coronavirus pandemic on families and individuals with autism spectrum disorders"

By clicking "Next" you confirm that you have read the detailed information about the study that can be downloaded [here](#).

VERY IMPORTANT: For most browser-settings the following applies when clicking on the download link: right click>open in the new tab. Otherwise you will not be able to continue with the questionnaire.

GR03

Declaration of consent

I was informed in writing about the nature, significance, scope and risks of the scientific study and had the opportunity to clarify my questions about it with the study managers. I was presented with the "Information for Participants" of the study and provided with a download link for this information.

I agree to participate in the study. My participation is voluntary.

I have the right to end my participation at any time without giving reasons and without any negative consequences for the future.

I accept that the personal data collected in the course of this scientific study:

- will at no time be linked to my real name, place of residence or e-mail address,
- be used exclusively for scientific research,
- will initially only be accessible to the scientists involved in this study (Prof. Dr. Stefan Schweinberger, Dr. Dana Schneider, Dr. Helene Kreysa, Samaneh Dastgheib, Andrea Kowallik and Cem Dogdu) and other members of the research group "Social Potential in Autism" at the Friedrich Schiller University of Jena. For possible continuation or replication work, the data can be made available to other researchers in completely anonymous form,
- will be stored, processed and analysed on electronic data carriers and the results obtained will be published in anonymous form.

By clicking "Next", you confirm your consent.

GR20

Please create an anonymous code.

The code consists of the first two letters of your mother's first name, the day you were born, and the last two letters of your own first name.

Example:

Mother = **Monica**

Your birthday = October **21**st

Your first name = **John**

Code: MO21HN

Please write your personal code in the blank text field.

GR19

By beginning the questionnaire, you confirm that you are the care-giver for a school-age child with a clinical diagnosis on the Autism Spectrum, living in the same household. GR05

Important: In the following questionnaire, we will refer to this child with **Autism** as **Child A**. We will also ask you to fill out some questions about one other child (**Child B**) who ideally lives in the same household. If you do not have another child in your household please report about another child with whom you are in close contact. We will refer to this child as **Child B**. Child B should **not** have a clinical diagnosis on the Autism Spectrum.

Please note that not all questions in this survey may cover all aspects that were important to you. Therefore, you will find a box for open comments at the end.

In this section, we ask you to provide us with some current information about yourself, your children, where you live, and how the pandemic has affected you. SD18

How many people (including yourself) currently live in your household most of the time? SI01

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ more than 10

For each household member (beginning with yourself) please provide some basic information.

SD19

I am giving detailed information about...

GR26

- ☐ Myself
- ☐ Child A- with Autism
- ☐ Child B- without Autism
- ☐ Other sibling
- ☐ Other parent
- ☐ Other household member

SD20

Age in full years

SI05

Gender

SA01

The person is...

- ☐ female
- ☐ male
- ☐ other
- ☐ prefer not to say

What is the profession of this person?

SA04

- ☐ Pupil/in school
- ☐ Training/apprenticeship
- ☐ University student
- ☐ Employee- Full time
- ☐ Employee- Part time
- ☐ Civil servant
- ☐ Self-employed
- ☐ Unemployed/seeking employment
- ☐ Other

BI37

Is a clinical diagnosis on the Autism Spectrum known for this person?

- ☐ Yes
- ☐ Suspected
- ☐ No

I am giving detailed information about...

GR27

- ☐ Myself
- ☐ Child A- with Autism
- ☐ Child B- without Autism
- ☐ Other sibling
- ☐ Other parent
- ☐ Other household member

SD49

Age in full years

SA83

Gender

SA02

The person is...

- ☐ female
- ☐ male
- ☐ other
- ☐ prefer not to say

What is the profession of this person?

SA38

- ☐ Pupil/in school
- ☐ Training/apprenticeship
- ☐ University student
- ☐ Employee- Full time
- ☐ Employee- Part time
- ☐ Civil servant
- ☐ Self-employed
- ☐ Unemployed/seeking employment
- ☐ Other

BI38

Is a clinical diagnosis on the Autism Spectrum known for this person?

- ☐ Yes
- ☐ Suspected
- ☐ No

I am giving detailed information about...

GR28

- ☐ Myself
- ☐ Child A- with Autism
- ☐ Child B- without Autism
- ☐ Other sibling
- ☐ Other parent
- ☐ Other household member

SD53

Age in full years

SA87

Gender

SA03

The person is...

- ☐ female
- ☐ male
- ☐ other
- ☐ prefer not to say

What is the profession of this person?

SA39

- ☐ Pupil/in school
- ☐ Training/apprenticeship
- ☐ University student
- ☐ Employee- Full time
- ☐ Employee- Part time
- ☐ Civil servant
- ☐ Self-employed
- ☐ Unemployed/seeking employment
- ☐ Other

BI39

Is a clinical diagnosis on the Autism Spectrum known for this person?

- ☐ Yes
- ☐ Suspected
- ☐ No

I am giving detailed information about...

GR29

- ☐ Myself
- ☐ Child A- with Autism
- ☐ Child B- without Autism
- ☐ Other sibling
- ☐ Other parent
- ☐ Other household member

SD54

Age in full years

SA91

Gender

SA16

The person is...

- ☐ female
- ☐ male
- ☐ other
- ☐ prefer not to say

What is the profession of this person?

SA40

- ☐ Pupil/in school
- ☐ Training/apprenticeship
- ☐ University student
- ☐ Employee- Full time
- ☐ Employee- Part time
- ☐ Civil servant
- ☐ Self-employed
- ☐ Unemployed/seeking employment
- ☐ Other

BI40

Is a clinical diagnosis on the Autism Spectrum known for this person?

- ☐ Yes
- ☐ Suspected
- ☐ No

I am giving detailed information about...

GR30

- ☐ Myself
- ☐ Child A- with Autism
- ☐ Child B- without Autism
- ☐ Other sibling
- ☐ Other parent
- ☐ Other household member

SD55

Age in full years

SA95

Gender

SA17

The person is...

- ☐ female
- ☐ male
- ☐ other
- ☐ prefer not to say

What is the profession of this person?

SA41

- ☐ Pupil/in school
- ☐ Training/apprenticeship
- ☐ University student
- ☐ Employee- Full time
- ☐ Employee- Part time
- ☐ Civil servant
- ☐ Self-employed
- ☐ Unemployed/seeking employment
- ☐ Other

BI41

Is a clinical diagnosis on the Autism Spectrum known for this person?

- ☐ Yes
- ☐ Suspected
- ☐ No

I am giving detailed information about...

GR46

- ☐ Myself
- ☐ Child A- with Autism
- ☐ Child B- without Autism
- ☐ Other sibling
- ☐ Other parent
- ☐ Other household member

SD56

Age in full years

SA99

Gender

SA18

The person is...

- ☐ female
- ☐ male
- ☐ other
- ☐ prefer not to say

What is the profession of this person?

SA42

- ☐ Pupil/in school
- ☐ Training/apprenticeship
- ☐ University student
- ☐ Employee- Full time
- ☐ Employee- Part time
- ☐ Civil servant
- ☐ Self-employed
- ☐ Unemployed/seeking employment
- ☐ Other

BI42

Is a clinical diagnosis on the Autism Spectrum known for this person?

- ☐ Yes
- ☐ Suspected
- ☐ No

Page 08

Diagnosis

For Child A, please indicate the severity of impairment due to their Autism Spectrum condition.BI29

- ☐ requires little or no support
- ☐ requires support
- ☐ requires substantial support
- ☐ requires very substantial support

Is Child A impaired in any other way?BI30

- ☐ yes (we would be very grateful if you could provide further information)
- ☐ no
- ☐ prefer not to say

Please indicate how much the following questions apply to Child A. Please tick one option per question only. **AQ02**

	strongly agree	agree	disagree	strongly disagree
1. S/he often notices small sounds when others do not.	☐	☐	☐	☐
2. S/he usually concentrates more on the whole picture, rather than the small details.	☐	☐	☐	☐
3. In a social group, s/he can easily keep track of several different people's conversations.	☐	☐	☐	☐
4. S/he finds it easy to go back and forth between different activities.	☐	☐	☐	☐
5. S/he doesn't know how to keep a conversation going with his/her peers.	☐	☐	☐	☐
6. S/he is good at social chit-chat.	☐	☐	☐	☐
7. When s/he is read a story, s/he finds it difficult to work out the character's intentions or feelings.	☐	☐	☐	☐
8. When s/he was in preschool, s/he used to enjoy playing games involving pretending with other children	☐	☐	☐	☐
9. S/he finds it easy to work out what someone is thinking or feeling just by looking at their face	☐	☐	☐	☐
10. S/he finds it hard to make new friends	☐	☐	☐	☐

Please indicate how much the following questions apply to Child B. Please tick one option per question only. **AQ03**

	strongly agree	agree	disagree	strongly disagree
1. S/he often notices small sounds when others do not.	☐	☐	☐	☐
2. S/he usually concentrates more on the whole picture, rather than the small details.	☐	☐	☐	☐
3. In a social group, s/he can easily keep track of several different people's conversations.	☐	☐	☐	☐
4. S/he finds it easy to go back and forth between different activities.	☐	☐	☐	☐
5. S/he doesn't know how to keep a conversation going with his/her peers.	☐	☐	☐	☐
6. S/he is good at social chit-chat.	☐	☐	☐	☐
7. When s/he is read a story, s/he finds it difficult to work out the character's intentions or feelings.	☐	☐	☐	☐
8. When s/he was in preschool, s/he used to enjoy playing games involving pretending with other children	☐	☐	☐	☐
9. S/he finds it easy to work out what someone is thinking or feeling just by looking at their face	☐	☐	☐	☐
10. S/he finds it hard to make new friends	☐	☐	☐	☐

What kind of accommodation do you live in?

DS01

- ☐ flat
- ☐ house
- ☐ other

Do any household members live somewhere else some of the time?

DS02

- ☐ No
- ☐ Yes, please specify

Does your accommodation have direct access to the outside?

DS03

- ☐ no
- ☐ balcony
- ☐ garden
- ☐ yard
- ☐ other, please specify

How many bedrooms are there in your accommodation?

DS04

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10 or more

Is there a private room for each child in the household?

DS18

- ☐ yes
- ☐ no
- ☐ unclear

Please indicate the population size of your community.

DC01

- ☐ less than one hundred
- ☐ between one hundred and one thousand
- ☐ between one thousand and ten thousand
- ☐ between ten thousand and one hundred thousand
- ☐ between one hundred thousand and one million
- ☐ more than one million

Which is the country, you're currently living in?

ED08

Country:

Were you born where you are currently living?

ED17

- ☐ yes, in this country and in this community / town
- ☐ yes, in this country, but in a different community / town
- ☐ in a different country
- ☐ prefer not to say

We are planning to circulate this survey in several different countries, so please let us know about the situation where you live.

CP04

Where you live, did the current pandemic lead to the following administrative restrictions at any time?

CP15

- ☐ School closures
- ☐ Complete lockdown

Where you live, are the following measures currently still in place?

CP02

	Yes	No	Partially	I don't know
School closures	☐	☐	☐	☐
Complete lockdown	☐	☐	☐	☐
Limits on groups of people	☐	☐	☐	☐
Limits on time and activities outside the house	☐	☐	☐	☐
Wearing protective clothing / face masks in public	☐	☐	☐	☐
Travel restrictions	☐	☐	☐	☐
Limits on sports and cultural activities	☐	☐	☐	☐
Restrictions for religious events	☐	☐	☐	☐
Restricted (non-corona) health-care and therapy options	☐	☐	☐	☐
Mandatory quarantine	☐	☐	☐	☐
Other (e.g., requirement / encouragement to carry tracking devices, documentation of purpose of visit or health status, ...)	☐	☐	☐	☐

What is your personal prediction about the future regarding the current crisis? When do you think the pandemic will be over?

CP03

- ☐ 1 month
- ☐ 3 months
- ☐ 6 months
- ☐ 1 year
- ☐ several years
- ☐ never

In the following, we are interested in how children and adolescents on the Autism spectrum spend their day.

AC01

For each of the following activities, please estimate how much time Child A (i.e., the autistic person you are reporting about) spent / spends on it in hours on a typical 24-hour day. Note, you can give proportions of the hour (e.g., 30 min = 0.5).

AB55

1. Use of digital devices (smartphone, tablet, laptop) for social communication (e.g. chatting with friends and family).

AC21

Before corona restrictions

[Please choose] ▼

At the peak of the crisis

AC58

[Please choose] ▼

Currently

AC59

[Please choose] ▼

2. Use of digital devices (smartphone, tablet, laptop) for entertainment (e.g., games, films, surfing the Web).

AC22

Before corona restrictions

[Please choose] ▼

At the peak of the crisis

AC60

[Please choose] ▼

Currently

AC68

[Please choose] ▼

3. Use of digital devices (smartphone, tablet, laptop) for education (e.g., homeschooling).

AA79 □

Before corona restrictions

[Please choose] ▼

At the peak of the crisis

AA78 □

[Please choose] ▼

Currently

AA77 ▼**4. Use of digital devices (smartphone, tablet, laptop) for – therapy, consultation, and coaching.**AA72

Before corona restrictions

 ▼

At the peak of the crisis

AA71 ▼

Currently

AA89 ▼**5. Special interests and hobbies.**AA66

Before corona restrictions

 ▼

At the peak of the crisis

AA65 ▼

Currently

AA64 ▼**6. Inside the house.**AD01

Before corona restrictions

 ▼

At the peak of the crisis

AD02 ▼

Currently

AD03 ▼AD07

7. In the garden or on the balcony.

Before corona restrictions

 ▼

At the peak of the crisis

 ▼AD08

Currently

 ▼AD09 **8. Outside (but not in your own garden or on your own balcony).**

Before corona restrictions

 ▼AD13

At the peak of the crisis

 ▼AD14

Currently

 ▼AD15 **9. Sleeping or in bed.**

Before corona restrictions

 ▼AD19

At the peak of the crisis

 ▼AD20

Currently

 ▼AD21

In the following, we are interested in how other children and adolescents spend their day.

AC07

For each of the following activities, please now estimate how much time Child B (i.e., the other child/adolescent you are reporting about) spent / spends on it in hours on a typical 24-hour day. Note again, you can give proportions of the hour (e.g., 30 min = 0.5).

AB59

1. Use of digital devices (smartphone, tablet, laptop) for social communication (e.g. chatting with friends and family).

AC89

Before corona restrictions

[Please choose] ▼

At the peak of the crisis

AC90

[Please choose] ▼

Currently

AC91

[Please choose] ▼

2. Use of digital devices (smartphone, tablet, laptop) for entertainment (e.g., games, films, surfing the Web).

AC95

Before corona restrictions

[Please choose] ▼

At the peak of the crisis

AC96

[Please choose] ▼

Currently

AC97

[Please choose] ▼

3. Use of digital devices (smartphone, tablet, laptop) for education (e.g., homeschooling).

AA81 □

Before corona restrictions

[Please choose] ▼

At the peak of the crisis

AA82 □

[Please choose] ▼

Currently

AA83 ▼**4. Use of digital devices (smartphone, tablet, laptop) for – therapy, consultation, and coaching.**AA87

Before corona restrictions

 ▼

At the peak of the crisis

AA88 ▼

Currently

AA70 ▼**5. Special interests and hobbies.**AA93

Before corona restrictions

 ▼

At the peak of the crisis

AA94 ▼

Currently

AA95 ▼**6. Inside the house.**AD25

Before corona restrictions

 ▼

At the peak of the crisis

AD26 ▼

Currently

AD27 ▼AD31

7. In the garden or on the balcony.

Before corona restrictions

 ▼

At the peak of the crisis

AD32 ▼

Currently

AD33 ▼**8. Outside (but not in your own garden or on your own balcony).**

Before corona restrictions

 ▼AD37

At the peak of the crisis

AD38 ▼

Currently

AD39 ▼**9. Sleeping or in bed.**

Before corona restrictions

 ▼AD43

At the peak of the crisis

AD44 ▼

Currently

AD45 ▼**The next questions concern changes in the health and well-being of children and adolescents.**

HB01

Please rate the following aspects for Child A at the present moment in time, compared to the time before the current pandemic.

HB04

	much decreased	slightly decreased	similar	slightly increased	much increased
General well-being	☐	☐	☐	☐	☐
Adaptation abilities	☐	☐	☐	☐	☐
Overall anxiety levels	☐	☐	☐	☐	☐
Emotional reactions	☐	☐	☐	☐	☐
Social behaviour	☐	☐	☐	☐	☐

Please rate the following aspects for Child B at the present moment in time, compared to the time before the current pandemic.

HB06

	much decreased	slightly decreased	similar	slightly increased	much increased
General well-being	☐	☐	☐	☐	☐
Adaptation abilities	☐	☐	☐	☐	☐
Overall anxiety levels	☐	☐	☐	☐	☐
Emotional reactions	☐	☐	☐	☐	☐
Social behaviour	☐	☐	☐	☐	☐

Please indicate how Child A responds to the following pandemic hygiene routines.

HB05

	not applicable	negative	neutral	positive
Maintaining physical distance to other people (1.5 m)	☐	☐	☐	☐
Regular hand-washing	☐	☐	☐	☐
Use of disinfectant	☐	☐	☐	☐
Wearing a face mask	☐	☐	☐	☐

Please indicate how Child B responds to the following pandemic hygiene routines.

HB07

	not applicable	negative	neutral	positive
Maintaining physical distance to other people (1.5 m)	☐	☐	☐	☐
Regular hand-washing	☐	☐	☐	☐
Use of disinfectant	☐	☐	☐	☐
Wearing a face mask	☐	☐	☐	☐

PedsQL™

PP80

Pediatric Quality of Life Inventory™

Version 4.0

Parent Report for Children (ages 8-12)

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PP53

All original items of the PedsQL are copyrighted. Therefore, we have only presented the parts that reflect our own instructions specific to this study.

You are now filling this in for Child A.

PQ49

Items related to the problems with physical functioning.

PQ02

1.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

2.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PQ66

3.

PQ67

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

4.

PI25

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

5.

PI27

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

6.

PI29

- ☐
- ☐
- ☐
- ☐
- ☐

7.

PI31

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PI33

8.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PP88

PedsQL™**Pediatric Quality of Life Inventory™**

Version 4.0

Parent Report for Children (ages 8-12)

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Items related to the problems with emotional functioning:

PI65

1.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

2.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PI66

3.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PI67 PI68

4.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

5.

PT01

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PedsQL™

PP89

Pediatric Quality of Life Inventory™

Version 4.0

Parent Report for Children (ages 8-12)

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Items related to the problems with social functioning:

PT25

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

2.

PT26

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

3.

PT27

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PT28

4.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

5. |

PT29

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

Items related to the problems with school functioning:

PP09

1.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

2.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PP10

3.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PP11 PP12

4.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

5.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PP13

PP49

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PedsQL™**PP84****Pediatric Quality of Life Inventory™**

Version 4.0

Parent Report for Children (ages 8-12)

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PP54**You are now filling this in for Child B.****PQ50**

Items related to the problems with physical functioning.

PQ73

1.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

2.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PQ74

3.

PQ75

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

4.

PI26

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

5.

PI28

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

6.

PI30

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

7.

PI32

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PI34

8.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PP96

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Items related to the problems with emotional functioning:

PI70

1.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

2.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PI71

3.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PI72 PI73

4.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

5.

PT03

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PP97

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Items related to the problems with social functioning:

PT30

1.

- ☐ 0-
☐ 1-
☐ 2-
☐ 3-
☐ 4-

2.

- ☐ 0-
☐ 1-
☐ 2-
☐ 3-
☐ 4-

PT31

3.

- ☐ 0-
☐ 1-
☐ 2-
☐ 3-
☐ 4-

PT32 PT33

4.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

5.

PT34

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

Items related to the problems with school functioning:

PP14

1.

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

2.

PP15

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

3.

PP16

- ☐ 0-
- ☐ 1-
- ☐ 2-
- ☐ 3-
- ☐ 4-

PP17

4.

- ☐ 0-
☐ 1-
☐ 2-
☐ 3-
☐ 4-

5.

- ☐ 0-
☐ 1-
☐ 2-
☐ 3-
☐ 4-

PP18

PP58

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13

Now please let us know how the current pandemic affected your entire family or household.

EF01

Please rate the following aspects for your family at the present moment in time, compared to the time before the current pandemic.

EF02

	much decreased	slightly decreased	similar	slightly increased	much increased
Overall stress levels	☐	☐	☐	☐	☐
Regular daily structure	☐	☐	☐	☐	☐
Conflict	☐	☐	☐	☐	☐
Time spent together	☐	☐	☐	☐	☐
Emotional closeness	☐	☐	☐	☐	☐

**During the current pandemic did you receive any form of support through the following people or institutions?
Please indicate all that apply.**

ST01 **Support by....**

- ☐ Close family
- ☐ Extended family and friends
- ☐ Neighbours
- ☐ Institutions
- ☐ Health service
- ☐ Government

Which (if any) forms of support did you find particularly useful and why?

ST02

Close family, because...

Extended family and friends, because...

ST05

Neighbours, because...

ST06

Institutions, because ...

ST07

Health service, because...

ST08

Government, because...

ST09

(How) did the current pandemic affect your child's ASD-specific educational and therapy/ rehabilitation activities?

ST03

Did you experience any other specific challenges during the current pandemic?

ST04

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oq

This is the open answer box that allows you to tell us about other aspects of the pandemic that were important to you.

ST38

ST42

Last Page

Thank you for completing this questionnaire!

We would like to thank you very much for helping us.

Your answers were transmitted, you may close the browser window or tab now.