




ARTICLE



<https://doi.org/10.1057/s41599-025-04388-9>

OPEN

Finnish parents' perception of the impact of COVID-19 on the lives of autistic adolescents

Kwok Ng ^{1,2,3✉}, Sanni Hiltunen⁴, Marleena Pekonen⁴ & Eija Kärnä⁴

The COVID-19 pandemic impacted autistic adolescents differently, but less is known about what aspects of their lives were the most affected. In this paper, we used a convenience sample ($n=323$) of Finnish parents of autistic adolescents who reported the perceived impact of COVID-19 on the lives of their autistic children. Data were analysed with content analyses and four themes emerged; studies, everyday life, interaction, and personal matters. The impact was considered to have been more negative (69%) than positive (31%). There were some mixed feelings towards the impact of COVID-19 and these were targeted particularly towards the way studies were carried out. Parents reported temporal negative impact of the pandemic such as, overall quality of schooling, changes to daily routines, lack of friendships, and reduced mental health. These areas should be monitored post-pandemic. In addition, parents reported their autistic adolescents were able to learn in an undistracted way, were supported by their family, had less exposure to stressful stimuli. The parents appreciated the opportunity to see their autistic child thrive. These were important learnings for designing personalised education for autistic adolescents, such as hybrid schooling and flexible supportive environments in a post-COVID-19 lockdown world.

¹Institute of Innovation and Sports Science, Lithuanian Sports University, Kaunas, Lithuania. ²Physical Activity for Health Research Centre, Health Research Institute, Department of Physical Education and Sport Sciences, University of Limerick, Limerick, Ireland. ³Faculty of Education, University of Turku, Rauma, Finland. ⁴School of Educational Sciences and Psychology, University of Eastern Finland, Joensuu, Finland. ✉email: kwok.ng@lsu.lt

The COVID-19 pandemic caused significant uncertainty around the world, leading to several changes to regular daily activities. Adolescents diagnosed with autism spectrum disorder (ASD) are one group of people who may have challenges adapting to these changes, especially because inflexibility and insistence on sameness are typical characteristics of having ASD (American Psychiatric Association, 2022; Uddin et al., 2015). There are a variety of studies on the impact of the pandemic on the lives of autistic children and adolescents (e.g., Baten et al., 2023; Fox et al., 2023; Ozsivadjian et al., 2023; Simpson & Adams, 2023). Each country had different ways of operationalising COVID-19 restrictions (Viner et al., 2020), and this is the first study to explore the impact on the lives of autistic adolescents in Finland from the perspective of parents.

Recently, the individual differences approach in autism research has emphasized the variation among autistic people, called for the avoidance of stereotypes (Bury et al., 2023), and the use of ableist language (Bottema-Beutel et al., 2021; Bury et al., 2023; Kenny et al., 2016). The terminology used in reference to persons diagnosed with autism spectrum disorder (ASD) has received increasing attention (Bury et al., 2023) and constant debate (Buijsman et al., 2023). Terminology that places person before identifier, termed person-first language (PFL), for example, ‘person with autism’, dominated autism research. However, terminology which places identifier before a person, termed identity-first language (IFL), for example, ‘autistic person’ seems to become more common (Buijsman et al., 2023; Shakes & Cashin, 2020). The American Psychological Association (American Psychological Association, 2020) advises using what is appropriate given the context, such as the preference of the participants themselves where, for example, the Autism Self Advocacy Network (Brown, 2012), seems to use IFL exclusively. In this study, the term “autistic adolescent” is used as it is the most accurate translation of the Finnish word “autismikirjon nuori”. In addition, researchers conducted a thorough study and concluded that IFL is the most favoured term in Finland (Dindar et al., 2023). Hence in this study, IFL is used, and as a paper based on textual quotes, the quotes used are of based on the way the participants terms were used. Yet, the term ASD is used when the text refers to the diagnosis.

Autistic adolescents experienced social withdrawal, loneliness, mood fluctuations, and anxiety during the COVID-19 lockdowns (Patel et al., 2023). Moreover, symptoms of ASD, such as anxiety, irritability, and restlessness were reported to have worsened (Ahmed et al., 2022). With the closure of schools, there were fewer chances to practice interaction skills (Latzner et al., 2021). The routines built over time had to change suddenly, which has been found to cause anxiety (Asbury et al., 2021). Yet, more time was spent with the family as quarantines were imposed (Latzner et al., 2021).

There were also reports of increased tension at home, with bullying and fighting between siblings in houses with autistic adolescents (Deniz et al., 2024), which could be the result of being indoors for too long (Fatehi et al., 2023). Despite these few negative reports, COVID-19 was a time when family members could be together for longer and it had a positive impact on the well-being of autistic adolescents, possibly due to decreased social demands (Latzner et al., 2021; Mumbardó-Adam et al., 2021; Simpson & Adams, 2023). In a review by Patel and colleagues (2023), two of the eight included studies highlighted improved relationships between parents and autistic adolescents as a positive outcome. Most notably, parents felt they were able to support their child’s autonomy, as well as adopt new structured routines. As an example of good practice, Delgi Espinosa and colleagues (2020) presented a structured daily outline for parents on what to do at home with the support of telehealth services that used applied behaviour analysis. Such programmes were very structured and in some cases, added additional stress

among parents (Milea-Milea et al., 2024). It was not rare for parents to report challenges in maintaining a suitable lifestyle at home and (remote) work, in addition to the difficulties to explain the COVID-19 restrictions and changes to routines to their autistic child (Fatehi et al., 2023). Other tools included freely available online behaviour and social support mechanisms to parents with autistic children (White et al., 2023). As reported in the literature, families experienced and handled times during the pandemic differently. There have been qualitative studies published (Deniz et al., 2024; Latzner et al., 2021), yet none so far have reported findings that relate to the experience of parents with autistic adolescents. Not least, none of the reports highlighted parents’ experience of COVID-19, with consideration of individual characteristics. Given the limited knowledge of the perceived impact of COVID-19 on autistic adolescents from the perspectives of the parents in Finland, the aim of this study was to investigate Finnish parents’ assessment of the impact the COVID-19 pandemic had on the lives of their autistic adolescent children.

Methods

Study design. This study was based on a convenience sample of parents or guardians who were available to complete an online survey during the spring of 2021. At this time, the pandemic was in a phase where, nationally, the students had returned back to school. As a part of the restrictions to prevent the acceleration of the epidemic, secondary education was regionally shifted to distance teaching in March 2021 (Mankki, 2024). Participants were recruited through national Autism Association groups as well as Autism related Facebook groups. According to the recommendations of the National Advisory on Research Integrity, approval by the institutional ethics committee was not needed, because the study consisted of an anonymous online survey of parents that did not put the individual at risk. The study was carried out within the remit of the Declaration of Helsinki in terms of ethical principles, such that participants were made aware of the research study and gave informed consent to participate, as well as, the completion of the survey was carried out voluntarily.

The online survey consisted of questions about the participant’s child. For example, the participant completed information on whether their child has autism or ASD diagnosis by a doctor. If they responded ‘No’ to the survey, they exited the study. Respondents who responded, ‘Yes’ to this question, were then asked to state the severity, with, “mild”, “moderate”, and “severe” as possible options. The participants were also asked to write the age of their child in years, and the gender of their child (male, female, other). The inclusion criterion for this study was for the autistic adolescent to be between 10 to 23 years old. The upper age limit of 23 years was chosen as autistic adolescents can continue their vocational training in job coaching after their training in preparatory training (Keyhitysvammaliitto [The Finnish Association on Intellectual and Developmental Disabilities], 2018; Ministry of Education and Culture, n.d.). Where the autistic adolescent was outside of this age range, the data was removed.

Data were converted to numeric data for statistical analyses. To improve the readability of the statistical analyses, responses from the severity groups of moderate and severe were combined. Contingency tables were performed to demonstrate the differences in responses between the severity levels of the children through Chi-square test of independence, after stratification by male and females. A second Chi-square test of independence was carried out to investigate the differences in the frequency of the positive and negative responses by severity level, after stratifying by gender. The low number of “other” gender responses ($n = 12$), were removed from the statistical analyses, but because the

opinions of parents remained important, that data remained in the qualitative data analyses.

There was a single open-ended question, “We are also interested to find out about the child’s well-being during the COVID-19 pandemic. Write how has COVID-19 had an impact on the well-being of your child (e.g. physical activity, screen time and sleep).” The survey had a free text box for participants to complete. The responses were analysed using inductive qualitative content analysis (Bengtsson, 2016). Before starting the analysis, each response was inserted into a cell in a spreadsheet. The same spreadsheet was used in the later phases of the analysis, which allowed the researchers to go back to original data and to verify the accuracy of the analysis. Initial analyses were performed by researchers (SH, MS) who were master degree students in educational sciences and had received training in qualitative content analyses prior to commencing the analyses. SH and MS went through the items and reduced the data by decontextualising and recontextualising the data. This included separating segments from the same respondent, where the tone of themes differed. For example, a respondent wrote, “There have been no changes to my child. Distance learning suited my child well. The virus itself caused concern for my child”. This was separated into three statements, in the following way. “There have been no changes to my child” was coded as a neutral statement. “Distance learning suited my child well” was coded as a positive statement, and “The virus itself caused concern for my child” was coded as a negative statement. In the next phase, these researchers (SH, MS) clustered the data into categories. Finally, in the compilation phase, they condensed categories into four main themes: interaction, everyday life, personal matters, and studies. To verify the accuracy of the analysis the first (KN) and last (EK) authors of this article checked the decontextualization and recontextualization of the data, then where necessary, classified the data again. At this stage, some minor changes were carried out by moving examples from the data into different categories. After a thorough check, there was no need to change the results of the compilation phase, i.e., the four main themes the students had discovered remained. The analysis continued by separating the data under the main four themes into positive, negative, or neutral statements. Upon inspection of the neutral statements, there were no other distinct themes than the recurring theme of no impact. Thus, neutral codes were not analysed any further. Furthermore, data were stratified by the severity of the child’s ASD. The raw units remained in the original language of the respondent. Quotes used to exemplify the results in this study were translated into English for reporting purposes. There was a lack of community involvement in this study, although the interaction and encouragement of parents to participate were through social media channels.

Results

Descriptive. The participants of the study were 323 parents or guardians who had an autistic adolescent. The breakdown of the participants’ child’s gender, age and severity is reported in Table 1.

From the 323 individual responses, there were 96 quotes that were coded as neutral, with some quotes not fitting into any such theme with quotes like, “nothing changed”. These responses were consistent and of short text. Therefore, it was not analysed further and the results presented in this study are only from positive and negative quotes. After cleaning, with some responses having more than one unit, there were 344 individual units and were coded under the main four themes in the following way: studies ($n = 128$), everyday life ($n = 92$), interaction ($n = 80$), and personal matters ($n = 44$). The length of the units varied from one sentence to several sentences.

Both negative ($n = 238$), and positive ($n = 106$) were related to (1) interaction (e.g, limited interaction with other people increased

Table 1 Sample characteristics by age group of adolescents on the autism spectrum.

Gender	ASD severity	10-12 y ($n = 107$)	13-15 y ($n = 120$)	16 y+ ($n = 96$)	Total ($n = 323$)
Male	Total	74	80	53	207
	Mild	41	36	22	99
	Moderate	29	40	22	91
	Severe	4	4	9	17
Female	Total	32	35	41	108
	Mild	17	22	20	59
	Moderate	13	9	19	41
	Severe	2	4	2	8
Other	Total	1	5	2	8
	Mild	1	2	2	5
	Moderate	0	3	0	3
	Severe	0	0	0	0

or decreased well-being), (2) studying (studying remotely was difficult or supported learning), (3) everyday routines (e.g., difficulties to cope with changes to everyday routines or staying home supported wellbeing), and (4) personal matters (e.g., difficulties to cope with the limitation of physical activities or staying at home increased the feelings of safety) as shown in Table 2.

According to the respondents of this study, the impact of the COVID-19 pandemic on the lives of autistic adolescents varied. Two-thirds of the participants informed that the pandemic had either a negative or positive impact on the lives of their autistic adolescents. Whereas one-third of the parents or guardians replied that the pandemic did not have a major impact on the lives of their autistic adolescents.

Demographic differences in experiences of COVID-19. The number of positive reports was statistically significantly higher among parents with females with mild ASD severity than those females with moderate or severe ASD ($X^2 = 8.09, p = 0.018$). Frequencies of positive, neutral and negative among parents with males did not differ between the ASD severity of their child (Fig. 1).

There were statistical differences in the frequency of the themes reported where parents had male children ($X^2 = 11.91, p = 0.008$), but not when the child was female. Parents with sons with mild ASD severity rarely reported issues about personal matters (7%), whereas this was more frequently reported when the parent’s son had moderate or severe ASD (22%). Conversely, the reports of the impact on studies were frequently reported (41%) when the parent’s son had mild ASD severity, whereas only 27% of the quotes were on this theme when the son had moderate or severe ASD (Fig. 2).

Negative impact on the lives of autistic adolescents. Over two-thirds of the units were coded as negative impacts from COVID-19. Negative experiences due to changes in everyday life were mentioned in 70 units (29%). During the COVID-19 pandemic, there were several changes in daily routines from pre-pandemic days. Access to rehabilitation was also restricted as in-person visits were closed and participation in organized leisure time activities was paused. A parent stated, “Routines have had to be changed, and that’s not a good thing for an autism spectrum student. Everything’s different than it used to be” (T180, mild ASD, 10–12 y, male).

The unit that was in relation to ‘Interaction’ appeared 64 times (27%). One example of interaction was the experience of isolation, and it was treated as a negative outcome. Furthermore, the pandemic decreased the child’s social skills. In particular, a parent said, “My youngster doesn’t talk about things, handles

Table 2 Number of quotes per positive and negative theme.

	Studies	Everyday life	Interaction	Personal matters	Total (n)
Negative	68	69	65	36	238
Positive	60	23	15	8	106
Total	128	92	80	44	344

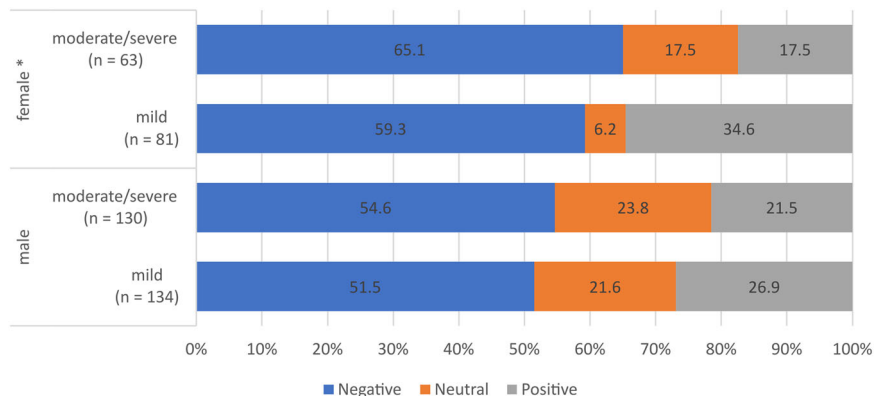


Fig. 1 Distribution of negative, neutral and positive responses by severity, stratified by gender.

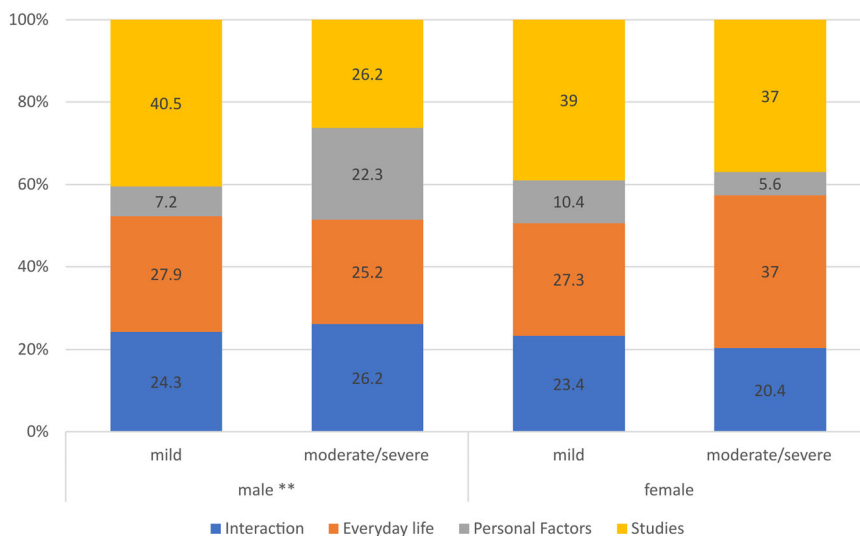


Fig. 2 Distribution of themes by severity and stratified by gender.

school well, is alone. I don't know what's going on. Isolated" (T282, mild ASD, 13–15 y, male).

Parents also noticed several personal matters that had been negatively impacted, such as an increased sense of loneliness. Furthermore, an increased sense of fear and anxiety, most likely a fear of getting the COVID-19, were reported by a parent, "My child does not want to go to any public places because he is afraid of the coronavirus. He did not like to go to public places even before and now the situation is really bad." (T332, moderate ASD, 10–12 y, male) The lockdown had also a negative impact on other aspects of the lives of autistic adolescents. Parents with autistic adolescents over the age of 16 y would describe the importance of socialising and other life skills. In particular, during lockdown, there were a lack of opportunities to interact, "Remote school has been bad for him because he has no other social life besides school" (T160, moderate ASD, 16y+, male).

Parents also noted in 68 units (29%), there were negative outcomes in the areas of studying. Unstructured days, access to

the teachers through online platforms, as well as a perceived lack of support and guidance for the student and parent were reported as negative outcomes. For example, "During remote schooling, he needed a lot of support from us, adults, [we] became overwhelmed and anxious when there was no clear schedule." (T300, moderate ASD, 10–12 y, male) The emphasis of 'we' in this sentence came from the notion that adults had to continue working and carry out parenting duties, in addition to being the teacher's assistant.

Positive impact on the lives of autistic adolescents. The most commonly reported type of positive impact was from the theme of studying, which occurred 60 times (57%). Distance learning during COVID-19 created a peaceful place to study, and it also increased the ICT skills of the students. In addition, the autistic adolescents received regular support from the teachers and the days were structured for remote learning. A parent wrote, "She's doing better than before. Reduced social contact has brought out

the best in her. [She] Enjoys being home. [She] doesn't need extra activities outside the home. Last spring, the remote studying suited her excellently." (T32, mild ASD, 10–12 y, female)

Parents also wrote positively about the interaction of their autistic child, and this was reported 15 times (14%). It would appear that having fewer contacts with other people allowed for more time with the family, as exemplified by the following, "There was less stress when there were fewer social contacts. More time spent with family" (173, mild ASD, 13–15 y, male).

Positive personal matters were reported 8 times (8%). For example, fewer sensory stimuli reduced stressful situations, "The impact has been positive because she does not like big crowds and the living environment remains pleasant to her when there are fewer visitors and fewer sensory stimuli" (T181, mild ASD, 10–12 y, female). Being able to be in close contact with the family was seen as a positive outcome, "Well-being improved. The child has studied remotely for over a year because of the risk group in the family. The corona year has been very rehabilitative." (T137, moderate ASD, 13–15 y, other).

There were also some positive outcomes to everyday life, as noted in 23 units (22%). With the pandemic, fewer leisure time activities took place for all children, which meant it was easier for children to reach other friends remotely during times of isolation. Unlike other aspects of the lockdown, the availability to use the outdoor environment was seen positively, "My child has not been affected much by the coronavirus because the outdoor playgrounds are open, and you can go for a walk." (T91, severe ASD, 13–15 y, male). Also, the use of facemasks or coverings hides the facial expressions making everyone appear equal. For example, a parent said, "My child loves to wear a special mask when he can hide behind it and now during the corona, it is normal, which he finds relieving." (T52, severe ASD, 16y+, male).

Mixed feelings about the COVID-19 pandemic. Both positive and negative impact of the pandemic were reported by the same parent. From parents with the negative comments, 19% also included positive comments. Whereas 42% of the positive comments also included negative comments. For example, in relation to everyday life, "Remote schooling was ok, but remote therapy did not, and this had an impact on his well-being" (T177, moderate ASD, 13–15 y, male). There were also mixed feelings concerning studies, "There were fewer distracting elements in distance learning, however, it was more difficult to follow the instruction" (T164, mild ASD, 16y+, male).

It appeared that studies had evolved throughout the pandemic "distance schooling was difficult in the beginning, it was difficult to learn under mother's guidance" yet, "he got used to the situation, and school went well, and it was easier to concentrate than in the big classroom" (T138, mild ASD, 10–12 y, male). The same participant also wrote about negative aspects of interactions, "due to COVID-19, contact with grandparents, aunts, uncles and cousins had reduced almost completely" (T138, mild ASD, 10–12 y, male).

When autistic adolescents transition into adulthood, they live separately from their parents. As such, the viewpoints from the parents may be a bit distal, but still relevant. A parent with an adult wrote about positive and negative aspects in the same response,

A 23-year-old, lives on his own in a different place. He has been very accepting of the restrictions and has also enjoyed distance learning. Friends are mainly at a distance anyway. The movement has stopped, it is difficult to leave home. It is more challenging than usual to balance study and leisure (T127, mild ASD, 16y+, male).

Although such an example seems that there was a positive impact on studies, there was also a negative impact on everyday

life. The mixed responses detailed how the changes in restrictions affected the studies as well as what it was like to carry out remote schooling at home,

For an AAC and signed speech user, you have exactly two options when distance learning doesn't technically work. [there was] homeschooling for half a year [and it] was 200% on my shoulders. The girl learned like a little angel, she easily reach her rehabilitation goals for the entire year. Then after half a year of home schooling, chaos, 20 + 20 [students] present, nothing was making any sense. The girl had to start using nappies. Exhausting. There were seven bags of laundry every day. School increases the risk of infection and more stress is induced when you don't know how to protect yourself when crowded. (T125, moderate ASD, 16y+, female).

As such, homeschooling was considered good when there was sufficient technology to support learning, as the rehabilitation goals for the year were reached in 6 months. Once returning back to school occurred, it became chaotic, not only for the reasons of incontinence but also greater distress from interaction with other people due to the fear and risk of getting COVID-19.

The COVID-19 restrictions brought about many changes to the daily routine of individuals. The impact was sometimes mixed with both positive and negative aspects in the dimension of everyday life, as reported,

Screen time had increased because leisure time activities were mainly done remotely on a computer. Swimming pools were closed... the museums were closed, and the child likes to be [there]. We spent more time as a family going to the nature" (T77, mild AS, 13–15 y, male).

Viewpoints of the impact of COVID-19 on autistic adolescents were, therefore, mixed between negative only, positive only, as well as a combination of positive and negative.

Discussion

According to the parents' responses to this study, the COVID-19 pandemic had a mixed impact on their autistic adolescents. It was informative to investigate the frequency of the perceived impact, as well as inductively categorised into four themes with a further quarter with neutral responses. One in five negative comments were only negative, whereas over two-fifths of positive comments were also countered by negative comments by the same parent. Statements about studies were the most common, everyday life, and interaction followed in frequency, and personal matters the least. These areas are discussed further.

The recurring focus on studies within the dataset allows researchers to identify it as a significant issue. Schooling has a central, and potentially challenging, position in the experiences of autistic adolescents during crises like the COVID-19 pandemic. The concern over lost learning skills has been repeated in other studies, to the extent that researchers found it to be the most prevalent worry among parents of children with ASD, regardless of the condition's severity (Fatehi et al., 2023). The parents' responses on the theme of studies were quite binary, as in either positive or negative. These findings resonate with earlier reports that half of parents (48%) reported negative impacts, a quarter (26%) with positive, 12% a mix, and 9% with no impact (Simpson & Adams, 2023). The perceptions positive or negative may be related to the way the parents manage at home with their child (Latzer et al., 2021). It was not known how many of the parents in our study had access to support, like what the parents in Michigan with the Spartans Caregiver Support programme had (White et al., 2023).

Similar to other studies, many parents of this study felt much burden on giving study guidance to their autistic adolescents at home at the same time as having to deal with changes in work circumstances (Baten et al., 2023). As the pandemic grew, lockdown measures were enforced quickly, teachers did not have much time to convert their traditional teaching modes to remote learning environments (Viner et al., 2020). Such drastic changes were expected to have a detrimental effect on student learning. There were dual adverse effects, as highlighted by Finnish teachers who reported the problems of using augmented IT at the beginning of the pandemic (Mankki, 2024). As reported in other studies, autistic children had lessons based on online meetings, followed by online or print-out materials (Kouroupa et al., 2022), yet the support given to parents was largely lacking (Thorell et al., 2022). Yet, addressing the need to support parents required planning. For example, too prescriptive telehealth support, based on applied behavioural analysis, was considered burdensome for parents to follow (Degli Espinosa et al., 2020). To our knowledge, no information was reported for parents in Finland. The challenges reported both in previous studies and our research were for example, parents' limited possibilities and time to concentrate on guiding children in learning, the children's difficulties, or reluctance to focus on learning, and children's difficulties or limitations to participate in online learning due to limited understanding of the material to be learned (Centeio et al., 2021; Korzycka et al., 2021; Thorell et al., 2022).

The findings from our study are not always bleak. The most often reported positive impact of COVID-19 on the lives of autistic adolescents in this study was related to schooling. Some parents thought their autistic children were able to flourish in the home environment, as opposed to the usual difficulties experienced at school. Such findings have led to the creation of a paediatrician's guide to work with autistic children (Sabapathy et al., 2022). The guide's aim was to make assessments that help find the most suitable type of education for autistic adolescents. The suitability of the environment for the child at home brought about positive insights from the parents. Researchers have reported similar findings from their own studies (Heyworth et al., 2021; Simpson & Adams, 2023). For example, Heyworth and colleagues (2021) discovered that the three key ingredients essential to the flourishing of autistic children, particularly in the context of learning, were the importance of connectedness, trusting relationships with family members through the sensory and social safety of home, and the flexibility to pace and structure learning to suit the individual child. Flexible studying arrangements such as studying partly at school and at home were also reported in our study. It would be worthwhile to consider such arrangements as an optimal way of schooling for some autistic adolescents, even after the COVID-19 restrictions had been lifted.

The parents of this study reported the impact of COVID-19 on the everyday living of their autistic adolescents in negative and positive ways. Parents gave numerous accounts of challenging situations in everyday life caused by restrictions from the COVID-19 pandemic that caused for example, fear and anxiety to their autistic adolescents. Parents have reported challenges in explaining to their autistic child the changes to normal routines (Fatehi et al., 2023), which in turn led to greater anxiety about how their child would cope with the abrupt changes in routines (Latzer et al., 2021). Routines and providing a structured environment promote the well-being of autistic adolescents, for example by reducing behaviour problems (Stoppelbein et al., 2016), yet the circumstances of the COVID-19 restrictions posed greater risks of poor well-being.

Generally speaking, the COVID-19 pandemic had a negative impact on the social lives of autistic children and adolescents (Patel et al., 2023; Sabapathy et al., 2022). The parents of this study made similar observations. Peer social interactions were reduced to

online only, and that was often seen negatively in autistic adolescents (Babb et al., 2021). The multidimensionality of friendships was broken down into a few factors. All individuals had to accept in-person meetings would not be possible and a need for creating new types of friendships was through technology (Fox et al., 2023). Yet, in our study, many parents described that social isolation caused by the pandemic had also been socially enjoyable for some autistic adolescents. This may be due to the unique features of interaction of autistic adolescents, which may differ from the interaction patterns of neurotypical peers (Heasman & Gillespie, 2019). Thus, the limited social interaction during COVID-19 reduced the pressure and discomfort related to social encounters and increased the social well-being of autistic adolescents.

During the spring of 2020 through 2021, the impact of the COVID-19 virus on health and society was unknown, and with no known working vaccine, this brought about rapid changes in personal matters (Pépin et al., 2020; Racine et al., 2020). Parents of this study often mentioned a fear of getting COVID-19 as the reason for their autistic adolescents' anxiety. This could be due to the unknown short- and long-term effects there were from getting the virus, coupled with it being highly contagious (Papa et al., 2020). Measures to prevent the spread of the virus included keeping their distance from others in public spaces, as well as wearing face masks or coverings (Finland, 2020). There were also changes to the ways schools opened up, particularly for students with special educational needs (Mankki, 2024). Wearing a mask or face covering was deemed as being uncomfortable for children, with common symptoms of headaches, speaking difficulties, and breathing discomfort (Assathiany et al., 2021). Yet from our study, we found that some autistic adolescents felt comfortable with masks. This may be explained by the use of wearing a face mask being associated with lower anxiety symptoms, especially among males (Xu et al., 2022). From our data, it was reported that it made interaction with other people less stressful since the masks covered faces, or that the autistic adolescents were able to feel equal to other people. This may seem to be a bit of a surprise, given the hypersensitivity issues often reported among autistic people. Differences in social cognition were common among autistic adolescents (Tamon et al., 2022), yet in a recent review of interventions that attempted to put masks on autistic people, all behaviour analytic intervention techniques led to positive results for wearing face masks (Cowell et al., 2023). Furthermore, autistic adults have also reported comfort in wearing and interacting with people with facemasks, as it meant they did not have to camouflage typical autistic facial responses (Clegg et al., 2023). Such nuances should be considered when considering individual differences towards the adoption of certain regulation measures.

There are several lessons learned from the experiences of autistic adolescents' parents regarding COVID-19. First, as the pandemic had many negative impacts on autistic adolescents' lives, it is important that societies are better prepared for sudden crisis situations by planning proactive and supportive measures (Mankki, 2024). The support measures envisaged should also take greater account the way the needs of vulnerable people are considered. Second, none of the impact was negative. There can be a positive impact on the lives of autistic adolescents throughout a crisis, such as the COVID-19 pandemic (Sabapathy et al., 2022). In this study, the parents were particularly informed about their adolescents' positive experiences on remote schooling during COVID-19. Consequently, it would be worthwhile to consider whether home-schooling or a hybrid model of schooling, i.e., studying some days during the week at school and some days at home, would be good as a more permanent schooling arrangement. As societies were unprepared for COVID-19, the measures were outlined by governments in a top-down approach (Viner et al., 2020). There was a lack of consultation with the public on

how these measures may be implemented and how they may affect people's day-to-day lives. Such insights from this study would be useful for future consultations. Finally, parents had mixed perceptions of the impact of COVID-19 on the lives of their autistic adolescents. By listening to various experiences, it was possible to get an understanding of the variety of circumstances of families with autistic adolescents who lived during the pandemic. Through listening to their experiences, crucial information on how society should be developed can be realised.

Limitations. This study included open-ended responses from over 300 parents of autistic adolescents yet, limited information was gathered about the circumstances of the lives of the adolescents. This was due to data protection protocols during data collection and limited the insights that were examined in this study, such as information about the intellectual development levels. The temporal nature of this study may be limited to reflecting on what happened during the times of the COVID-19 restrictions, but we believe it is important to understand the impact of the COVID-19 pandemic during the age of adolescence. The sample was from a convenience sample, recruited from social media. Therefore, the representativeness of all autistic adolescents should be considered with caution. Rather, the study was used as a way to gather insights from a comprehensive data set. Follow-up questions were not possible via the online platform, hence limiting the scope to the first and primary things the respondents wanted to report in their responses.

Conclusion

There were mixed perceptions on the way COVID-19 restrictions had an impact on autistic adolescents. Approximately half of the aspects mentioned described the negative impact of COVID-19 on well-being, a quarter described positive effects, and another quarter of responses indicated that the pandemic did not impact autistic adolescents' well-being. As the restrictions ended, the temporal negative impact of the pandemic included concerns about the overall quality of schooling, changes to daily routines, lack of friendships, and reduced mental health. These areas should be monitored, especially among autistic adolescents as they develop into adults in society. There were also several positive experiences noted coming from the pandemic. These included finding ways to learn in an undistracted way, being in a supportive family environment, less exposure to stressful stimuli, and parents appreciating the opportunity to see their own child thrive. Based on the evidence identified in this study, there were positive impacts of COVID-19 on schooling. It is recommended that education providers explore and implement strategies informed by these findings. Furthermore, teachers could plan alternative and flexible teaching arrangements such as hybrid schooling for both unexpected conditions and current teaching arrangements.

Data availability

The data that support the findings of this study are available from the corresponding author (KN), upon reasonable request.

Received: 21 May 2024; Accepted: 14 January 2025;

Published online: 21 January 2025

References

Ahmed S, Hanif A, Khaliq I, Ayub S, Saboor S, Shoib S, Jawad MY, Arain F, Anwar A, Ullah I, Naveed S, Mahmood Khan A (2022) Psychological impact of the COVID-19 pandemic in children with autism spectrum disorder—A

- literature review. *International Journal of Developmental Disabilities*, 1–11. <https://doi.org/10.1080/20473869.2022.2066248>
- American Psychiatric Association. (2022) *Diagnostic and Statistical Manual of Mental Disorders* (Fifth Edition, Text Revision). American Psychiatric Association. <https://doi.org/10.1176/appi.books.9780890425787>
- American Psychological Association. (2020). *Disability*. Publication Manual of the American Psychological Association (7th Ed.). <https://apastyle.apa.org/style-grammar-guidelines/bias-free-language/disability>
- Asbury K, Fox L, Deniz E, Code A, Toseeb U (2021) How is COVID-19 affecting the mental health of children with special educational needs and disabilities and their families? *Journal of Autism and Developmental Disorders* 51(5):1772–1780. <https://doi.org/10.1007/s10803-020-04577-2>
- Assathiany R, Salinier C, Béchet S, Dolard C, Kochert F, Bocquet A, Levy C (2021) Face masks in young children during the COVID-19 pandemic: parents' and pediatricians' point of view. *Frontiers in Pediatrics* 9:676718. <https://doi.org/10.3389/fped.2021.676718>
- Babb S, Raulston TJ, McNaughton D, Lee J-Y, Weintraub R (2021) The effects of social skill interventions for adolescents with autism: a meta-analysis. *Remedial and Special Education* 42(5):343–357. <https://doi.org/10.1177/0741932520956362>
- Baten E, Vlaeminck F, Mués M, Valcke M, Desoete A, Warreyn P (2023) The impact of school strategies and the home environment on home learning experiences during the COVID-19 pandemic in children with and without developmental disorders. *Journal of Autism and Developmental Disorders* 53(4):1642–1672. <https://doi.org/10.1007/s10803-021-05383-0>
- Bengtsson M (2016) How to plan and perform a qualitative study using content analysis. *NursingPlus Open* 2:8–14. <https://doi.org/10.1016/j.npls.2016.01.001>
- Bottema-Beutel K, Kapp SK, Lester JN, Sasson NJ, Hand BN (2021) Avoiding Ableist language: suggestions for autism researchers. *Autism in Adulthood* 3(1):18–29. <https://doi.org/10.1089/aut.2020.0014>
- Brown L (2012) Identity-First Language—Autistic Self Advocacy Network. <https://autisticadvocacy.org/about-asan/identity-first-language/>
- Buijsman R, Begeer S, Scheeren AM (2023) Autistic person' or 'person with autism'? Person-first language preference in Dutch adults with autism and parents. *Autism* 27(3):788–795. <https://doi.org/10.1177/13623613221117914>
- Bury SM, Jellett R, Spoor JR, Hedley D (2023) It Defines Who I Am' or 'It's Something I Have': What language do [Autistic] Australian adults [on the Autism Spectrum] prefer? *Journal of Autism and Developmental Disorders* 53(2):677–687. <https://doi.org/10.1007/s10803-020-04425-3>
- Centeio E, Mercier K, Garn A, Erwin H, Marttinen R, Foley J (2021) The success and struggles of physical education teachers while teaching online during the COVID-19 pandemic. *Journal of Teaching in Physical Education* 40(4):667–673. <https://doi.org/10.1123/jtpe.2020-0295>
- Clegg A, Wood J, Hobson H, Sedgewick F (2023) The experiences of autistic people when facemask wearing and interacting with masked individuals. *Autism in Adulthood*, aut.2022.0091. <https://doi.org/10.1089/aut.2022.0091>
- Cowell R, Vostanis A, Langdon PE (2023) Increasing face mask wearing in autistic individuals using behavior analytic interventions: a systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-023-06128-x>
- Degli Espinosa F, Metko A, Raimondi M, Impenna M, Scognamiglio E (2020) A model of support for families of children with autism living in the COVID-19 lockdown: lessons from Italy. *Behavior Analysis in Practice* 13(3):550–558. <https://doi.org/10.1007/s40617-020-00438-7>
- Deniz E, Fox L, Asbury K, Toseeb U (2024) Sibling relationships and parental interventions to sibling bullying during COVID-19: A qualitative comparison of British and Turkish families of autistic adolescents. *Autism & Developmental Language Impairments* 9:23969415241268242. <https://doi.org/10.1177/23969415241268242>
- Dindar K, Kilpiä A, Kämäräinen A, Pihlainen K, Pukki H-K, Kärnä E (2023) Sidosryhmien näkemyksiä autismikirjoa koskevasta terminologiasta Suomessa [Stakeholders views on autism spectrum terminology in Finland]. *Oppimisen ja oppimisvaikeuksien erityislehti - NMI Bulletin* 33(2):19–35
- Fatehi M, Fatehi L, Mowbray O (2023) Autism spectrum disorder, parent coping, and parent concerns during the COVID-19 pandemic. *Children and Youth Services Review* 149:106923. <https://doi.org/10.1016/j.childyouth.2023.106923>
- Finland P. (2020) *Valmiuslain käyttöönottaminen korona-aikana [Introduction of the emergency powers act during the COVID-19 period]*. https://www.eduskunta.fi/FI/naineduskuntatoimii/kirjasto/aineistot/kotimainen_oikeus/LATI/Sivut/valmiuslain-kayttoonottaminen-koronavirustilanteessa.aspx
- Fox L, Asbury K, Code A, Toseeb U (2023) Parents' perceptions of the impact of COVID-19 and school transition on autistic children's friendships. *Autism* 27(4):983–996. <https://doi.org/10.1177/13623613221123734>
- Heasman B, Gillespie A (2019) Neurodivergent intersubjectivity: Distinctive features of how autistic people create shared understanding. *Autism* 23(4):910–921. <https://doi.org/10.1177/1362361318785172>
- Heyworth M, Brett S, Houting JD, Magiati I, Steward R, Urbanowicz A, Stears M, Pellicano E (2021) It just fits my needs better": Autistic students and parents'

- experiences of learning from home during the early phase of the COVID-19 pandemic. *Autism & Developmental Language Impairments* 6:239694152110576. <https://doi.org/10.1177/23969415211057681>
- Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E (2016) Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism* 20(4):442–462. <https://doi.org/10.1177/1362361315588200>
- Keyhitysvammaliitto [The Finnish Association on Intellectual and Developmental Disabilities]. (2018). *Employment*. <https://www.keyhitysvammaliitto.fi/english/intellectual-disability/employment/>
- Korzycza M, Bójko M, Radiukiewicz K, Dzielska A, Nałęcz H, Kleszczewska D, Małkowska-Szkatnik A, Fijałkowska A (2021) Demographic analysis of difficulties related to remote education in Poland from the perspective of adolescents during the COVID-19 pandemic. *Annals of Agricultural and Environmental Medicine* 28(1):149–157. <https://doi.org/10.26444/aaem/133100>
- Kouroupa A, Allard A, Gray KM, Hastings RP, Heyne D, Melvin GA, Tonge BJ, Totsika V (2022) Home schooling during the COVID-19 pandemic in the United Kingdom: The experience of families of children with neurodevelopmental conditions. *Frontiers in Education* 7:974558. <https://doi.org/10.3389/educ.2022.974558>
- Latzter TI, Leitner Y, Karnieli-Miller O (2021) Core experiences of parents of children with autism during the COVID-19 pandemic lockdown. *Autism* 25(4):1047–1059. <https://doi.org/10.1177/1362361320984317>
- Mankki V (2024) (Re)thinking teaching after COVID-19 school lockdown: A longitudinal study of Finnish primary school teachers' expectations for, and perceptions of, change. *Education* 3-13:1–12. <https://doi.org/10.1080/03004279.2024.2325518>
- Milea-Ac, Fernández-Pérez D, Toledano-González A (2024) The psychological impact of the COVID-19 pandemic on children/adolescents with ASD and their family environment: A systematic review. *European Child & Adolescent Psychiatry* 33(1):203–228. <https://doi.org/10.1007/s00787-023-02151-6>
- Ministry of Education and Culture. (n.d.). *Option for completing compulsory education after comprehensive school*. Ministry of Education and Culture. Retrieved 18 September 2024, from <https://okm.fi/documents/1410845/122468998/Compulsory+education-EN.pdf/>
- Mumbardó-Adam C, Barnet-López S, Balboni G (2021) How have youth with Autism Spectrum Disorder managed quarantine derived from COVID-19 pandemic? An approach to families perspectives. *Research in Developmental Disabilities* 110:103860. <https://doi.org/10.1016/j.ridd.2021.103860>
- Ozsivadjian A, Milner V, Pickard H, Hollocks MJ, Gaigg SB, Colvert E, Happé F, Magiati I (2023) Autistic and non-autistic young people's and caregivers' perspectives on COVID-19-related schooling changes and their impact on emotional well-being: An opportunity for change? *Autism* 27(5):1477–1491. <https://doi.org/10.1177/13623613221140759>
- Papa SM, Brundin P, Fung VSC, Kang UJ, Burn DJ, Colosimo C, Chiang H-L, Alcalay RN, Trenkwalder C, and the MDS-Scientific, I. C. (2020) Impact of the COVID-19 pandemic on Parkinson's disease and movement disorders. *Movement Disorders* 35(5):711–715. <https://doi.org/10.1002/mds.28067>
- Patel B, Patel B, Srinivasan S (2023) Effects of the COVID-19 pandemic on children and youth with autism spectrum disorder: a concise systematic review. *Review Journal of Autism and Developmental Disorders* 11:1–7. <https://doi.org/10.1007/s40489-023-00391-5>
- Pépin JL, Bruno RM, Yang R-Y, Vercamer V, Jouhaud P, Escourrou P, Boutouyrie P (2020) Wearable activity trackers for monitoring adherence to home confinement during the COVID-19 pandemic worldwide: data aggregation and analysis. *Journal of Medical Internet Research* 22(6):e19787. <https://doi.org/10.2196/19787>
- Racine N, Cooke JE, Eirich R, Korczak DJ, McArthur B, Madigan S (2020) Child and adolescent mental illness during COVID-19: A rapid review. *Psychiatry Research* 292:113307
- Sabapathy T, Goss M, Borelli JL, Steinberg-Epstein R (2022) A Pediatrician's Guide to Working with Children on the Autism Spectrum in Coronavirus Disease 2019 and Beyond: Retrospect and Prospect. *Advances in Pediatrics* 69(1):41–58. <https://doi.org/10.1016/j.yapd.2022.04.001>
- Shakes P, Cashin A (2020) An analysis of Twitter discourse regarding identifying language for people on the autism spectrum. *Issues in Mental Health Nursing* 41(3):221–228. <https://doi.org/10.1080/01612840.2019.1648617>
- Simpson K, Adams D (2023) Brief report: covid restrictions had positive and negative impacts on schooling for students on the autism spectrum. *Journal of Autism and Developmental Disorders* 53(7):2921–2927. <https://doi.org/10.1007/s10803-022-05451-z>
- Stoppelbein L, Biasini F, Pennick M, Greening L (2016) Predicting internalizing and externalizing symptoms among children diagnosed with an autism spectrum disorder: the role of routines. *Journal of Child and Family Studies* 25(1):251–261. <https://doi.org/10.1007/s10826-015-0218-3>
- Tamon H, Itahashi T, Yamaguchi S, Tachibana Y, Fujino J, Igarashi M, Kawashima M, Takahashi R, Shinohara NA, Noda Y, Nakajima S, Hirota T, Aoki YY (2022) Autistic children and adolescents with frequent restricted interest and repetitive behavior showed more difficulty in social cognition during mask-wearing during the COVID-19 pandemic: A multisite survey. *BMC Psychiatry* 22(1):608. <https://doi.org/10.1186/s12888-022-04249-8>
- Thorell LB, Skoglund C, De La Peña AG, Baeyens D, Fuermaier ABM, Groom MJ, Mammarella IC, Van Der Oord S, Van Den Hoofdakker BJ, Luman M, De Miranda DM, Siu AFY, Steinmayr R, Idrees I, Soares LS, Sörlin M, Luque JL, Moscardino UM, Roch M, Christiansen H (2022) Parental experiences of homeschooling during the COVID-19 pandemic: Differences between seven European countries and between children with and without mental health conditions. *European Child & Adolescent Psychiatry* 31(4):649–661. <https://doi.org/10.1007/s00787-020-01706-1>
- Uddin LQ, Supekar K, Lynch CJ, Cheng KM, Odriozola P, Barth ME, Phillips J, Feinstein C, Abrams DA, Menon V (2015) Brain state differentiation and behavioral inflexibility in autism. *Cerebral Cortex* 25(12):4740–4747. <https://doi.org/10.1093/cercor/bhu161>
- Viner RM, Russell SJ, Croker H, Packer J, Ward J, Stansfield C, Mytton O, Bonell C, Booy R (2020) School closure and management practices during coronavirus outbreaks including COVID-19: A rapid systematic review. *The Lancet Child & Adolescent Health* 4(5):397–404. [https://doi.org/10.1016/S2352-4642\(20\)30095-X](https://doi.org/10.1016/S2352-4642(20)30095-X)
- White AN, Brodhead MT, Sipila-Thomas ES, Miranda DRG, Long HM, Fisher MH (2023) Spartan caregiver support: program description and key findings during Michigan's stay-at-home order. *Advances in Neurodevelopmental Disorders* 7(3):459–468. <https://doi.org/10.1007/s41252-022-00281-7>
- Xu Q, Mao Z, Wei D, Fan K, Liu P, Wang J, Wang X, Lou X, Lin H, Wang C, Wu C (2022) Association between mask wearing and anxiety symptoms during the outbreak of COVID 19: A large survey among 386,432 junior and senior high school students in China. *Journal of Psychosomatic Research* 153:110709. <https://doi.org/10.1016/j.jpsychores.2021.110709>

Author contributions

KN curated data collection, analysed the data, drafted, and edited the manuscript. SH and MP analysed the data and wrote drafts of the manuscript while completing their master studies. EK curated data collection, analysed the data, drafted and edited the manuscript.

Competing interests

The authors declare no conflicts of interest. Prof. Eija Kärnä received funding from the Research Council of Finland. Funders were not involved in any part of the study.

Ethical approval

The research was conducted as survey on consenting adults (parents) who volunteered to answer questions. Under the University of Eastern Finland's ethics regulations, such research does not require ethical committee approval as it was not deemed to contact any of the six areas outlined by the Finnish National Board on Research Integrity (<https://tenk.fi/en/ethical-review/ethical-review-human-sciences>).

Informed consent

All participants gave informed consent prior to completing the survey.

Additional information

Correspondence and requests for materials should be addressed to Kwok Ng.

Reprints and permission information is available at <http://www.nature.com/reprints>

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.



Open Access This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License, which permits any non-commercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if you modified the licensed material. You do not have permission under this licence to share adapted material derived from this article or parts of it. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by-nc-nd/4.0/>.

© The Author(s) 2025