



Pandemic, lockdown, and autism: from distress to solutions

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The COVID-19 pandemic has an important impact on the entire world and has significantly changed the lives of many families. Just like everyone else, autistic children and their families lived through the trials of the lockdown and physical distancing. However, no data currently exists on the experiences of autistic¹ children and their families during this situation, or on the resources helpful to their well-being.

As researchers and clinicians, we were interested in the needs of autistic children (aged 2 to 18) and their families during this crisis, in order to propose recommendations that would guide support services. We therefore surveyed parents and children themselves.

To date, 90 parents have taken our survey, largely through an online questionnaire. 53 autistic children (4 to 18 years old) have also provided their opinion on the current situation. In this article, we would like to summarise initial results.

73% of parents declared not being more concerned than usual about their child's development.

How to explain this results? Is this due to the fact that:

Parents

83 %

Reported a high level of knowledge about autism

79%

reported not feeling depressed in the wake of stressful situations

52%

do not perceive the pandemic as a great source of stress, but rather report seeing it as an opportunity to make the most of quality time

Only further analyses will allow us to answer these questions.

Two different parental profiles emerge from the data. For some parents, the situation has not been problematic:

The lockdown was absolutely not a difficult period for him nor for us. In fact, the ability to dedicate himself to his passion in an independent way was very positive for all of us. – Parent of a 16-year-old autistic boy.

For others, the situation has caused significant distress:

We felt left to our own devices, no one stepped in to help us during this time. It is the worst thing my boy has lived through, and us as well as his parents. – Parent of a 15-year-old autistic boy.

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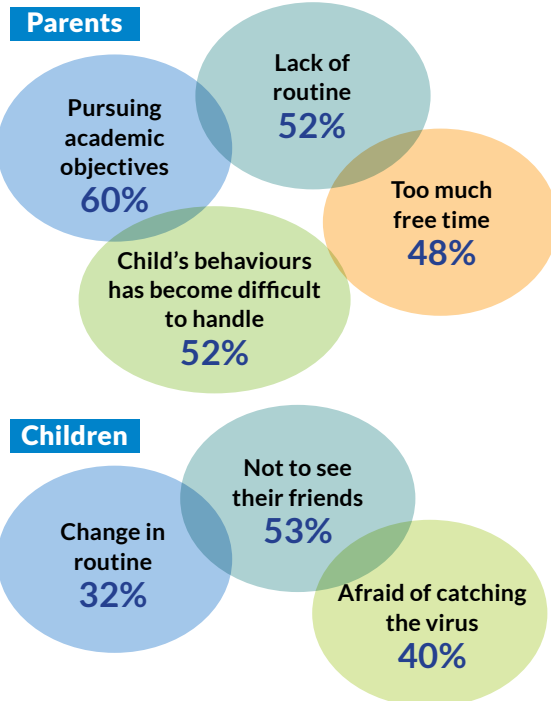
¹ Autistic refers to a diagnosis of an Autism Spectrum Disorder (according to DSM-5), or Asperger's Syndrome, autism, Pervasive Developmental Disorder-not otherwise specified (according to DSM-IV-TR).



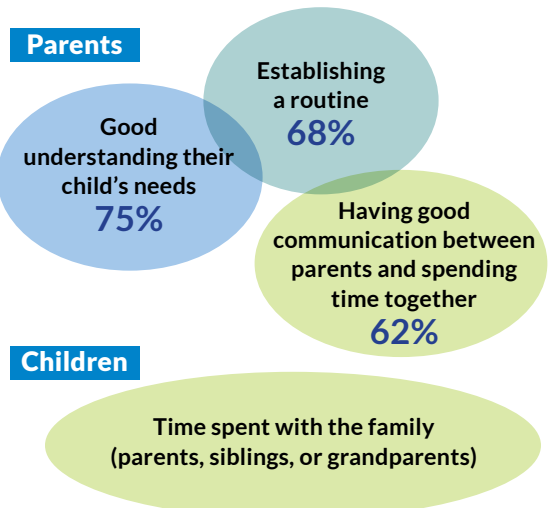
Ensure that information and guidelines issued by authorities are fair and coherent.

Which daily challenges were reported?

Many factors were identified as having adverse effects on daily life.



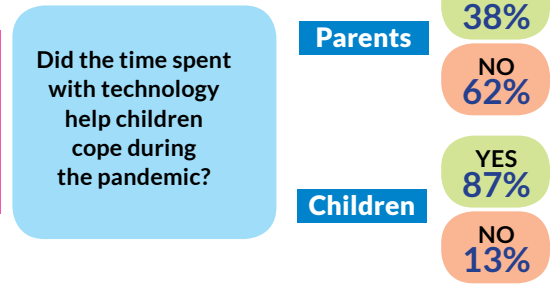
Which factors facilitated adaptation?



Special interests: challenge or solution?



For 66% of parents, free access to technology was the first accommodation made to preserve family balance.



In sum, special interests, particularly for technology (computer, tablet, video games, cell phone) occupied a large space in autistic children's daily lives during the lockdown. The role these interests play must therefore be better understood by parents in order to integrate them appropriately into daily life.

How can we better support children and their families? Some starting points.

Parents identified several measures that organisations could implement to increase their well-being.

For the GOVERNMENT

- Ensure that information and guidelines issued by authorities are fair and coherent. This information is important, as parents indicated that 51% of children obtained information about COVID-19 through the media:

A clear and consistent message from the Ministry of Education would have been necessary. After having sent the kids off wishing them a great summer and repeating that schoolwork was optional and would not count towards their final report card, it didn't make sense to finally mandate school work and say it would possibly be graded. My son mostly retained the first and second message. It was very hard to get him to do more than the bare minimum. – Parent of an autistic 16-year-old boy

- Offer respite and financial compensation:

The government could have helped by offering money to go towards some respite. I was left to fend for myself which caused a lot of anxiety until I experienced parental burnout. – Parent of an 11-year-old autistic girl.

For HEALTH AND SOCIAL SERVICES

- Maintain specialised services and facilitate access to autism specialists:

We would have liked for services supporting families with an autistic child to be considered as essential services. – Parent of a 6-year-old autistic boy.

For EDUCATIONAL SERVICES

- Accelerate the setup of distance learning and ensure follow ups with school staff so that children can follow a routine and familiarise themselves with adapted teaching tools:

Call more frequently to check in on the needs of the child and their family. – Parent of an 18-year-old autistic girl.

- Offer opportunities for children to socialise, to combat social isolation:


Organise groups in CEGEP of students who have an autism diagnosis or other similar condition. It would have been helpful for him to know that he was not the only one dealing with anxiety. – Parent of an 18-year-old autistic boy. It would be nice if he could have a spot at day-care and could see other children. – Parent of a 4-year-old autistic boy.

For PROFESSIONAL ENVIRONMENTS

- Build awareness amongst employers to allow better understanding and flexibility in terms of managing work:

Take into account the situations of families living with an autistic child and allow for some exceptions. – Parent of an 8-year-old autistic child.

In sum, these results suggest that lockdown was experienced in very heterogeneous ways by parents as well as children. Although parents attempted to deploy numerous strategies to facilitate daily adaptation, these preliminary results reveal the necessity to put in place **more supportive measures** that promote family well-being. Parents highlighted that **adapted** measures which considered autistic children's needs and particularities were **crucial** to put in place. Autistic children indicated the need to **maintain contact with their peers**.

A huge thank you to all the parents who took the time to participate online or by interview, and children who shared their lived experience with us. We would also like to thank the research assistants for their incredible work: Katarina Sotelo, Jade Desrosiers, Agnès Ethier and Chloé Belley. 



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