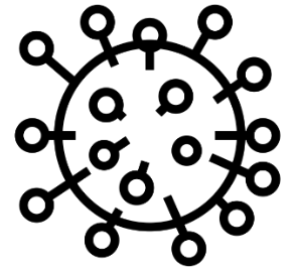


Life during COVID-19 for autistic people and their families



Easy Read Summary

July 2020



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Transformative Research for Social Justice



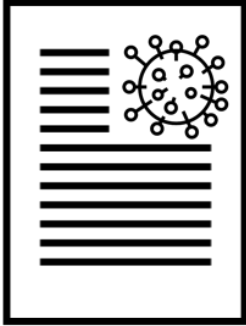
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reframing
AUTISM
respect accept embrace empower



This report is about the COVID-19 pandemic. It looks at the impact of the pandemic on autistic people and their families.

The report is based on a project. The project was done by autistic and non-autistic researchers from:

- Macquarie University
- Reframing Autism
- Wellcome Trust and University College London
- RMIT University
- University of Western Australia
- University of Sydney

The report was done by:

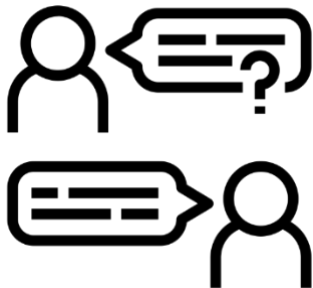
- Liz Pellicano
- Simon Brett
- Jac den Houting
- Melanie Heyworth
- Iliana Magiati
- Robyn Steward
- Anna Urbanowicz
- Marc Stears

You can read the original report here:

<https://www.sydney.edu.au/dam/corporate/documents/sydney-policy-lab/everyday-experiences-of-autistic-people-during-covid-19---report---july-2020.pdf>



COVID-19 meant that people had to stay at home during lockdown. We wanted to know how this affected autistic people and their families.



We spoke to 131 people including

- 35 autistic adults
- 45 non-autistic parents of autistic children
- 35 autistic parents of autistic children
- 16 young autistic people. They were between 12 and 18 years old.

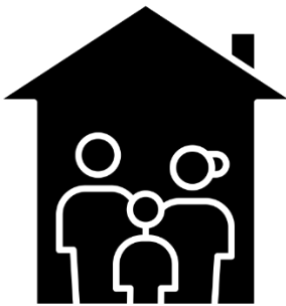


We asked them about

- Staying at home
- Work and study
- Connecting with other people
- Wellbeing
- Supports and services
- Life after COVID-19



People said there were some good things about lockdown.



Some people liked working and studying from home.



Some people were able to use the telephone or online video. They could speak to their doctor, mental health worker or other support people using technology.

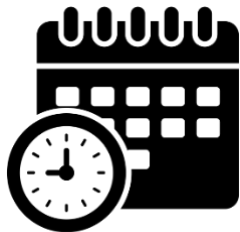


Some people felt “less stressed” or “more relaxed” than usual during lockdown.



Staying at home meant that some people had time for their hobbies like:

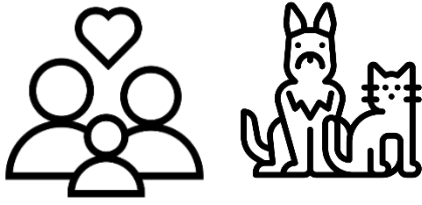
- Cooking
- Writing and drawing
- Sewing
- Playing video games



Some schools changed their timetables. For young people, this meant they had more time “between classes to walk around”. Or, they had time “to talk to my family, which is good”.



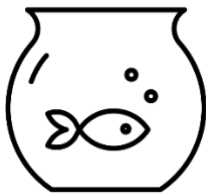
One young autistic person said, “now... it's do it at your own pace”.



Many people enjoyed having more time with family. Family included pets for people.



Some people said, “increased family time” meant they felt closer as a family.



People said that their pets helped them feel good. One autistic adult said, “it’s very relaxing watching my fish – good for my anxiety”.



And one young person said it’s nice to have their “cat join me in a lot of classes”.



Some people said they felt connected to other people.



Some said that “people have become a lot more friendly and open”.



Online connections made people feel good too. One autistic adult said that they “have a good community here but COVID-19 has made it even stronger”.



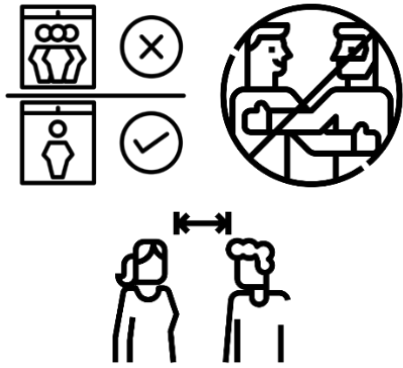
People also told us about some bad times during lockdown.



One autistic adult said she was “running out of money”. She could not see how she could make money. She worried about getting a job.



Young autistic people were worried about other people. They were worried about the “many people who have lost their jobs”. They worried about “whether we will be able to financially recover from it”.



Lockdown changed what people could do every day.



One autistic adult said: “It’s been really crappy...”. That adult said they missed having any control. It made their life feel chaotic.

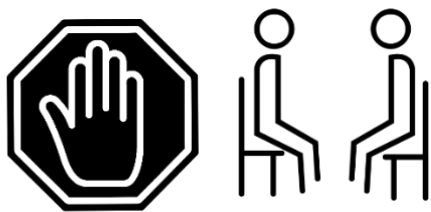


For some adults, their anxiety or depression got worse. Some children also had worse anxiety or depression. Some people needed medication to help. Others needed medical help.



Some people did not like using the telephone or online video.

They did not speak to their doctor, mental health worker or other support people.



People could not always have therapy during lockdown. One young autistic person did not want to speak with their therapist online. So, they stopped appointments.



Some young people did not like using online video to do school. They missed regular contact with their teachers.



Sometimes, online school did not work well. One parent said that “no thought” had been made to help autistic children do school at home. Another parent said it caused “intense stress and anxiety”.



People were not happy with the advice from the government.

They said the advice was not given “as well as it could be”.



People got worried about which

information was right. They

worried about where to find

information. They worried

because there were lots of

quick changes.



Autistic adults were anxious

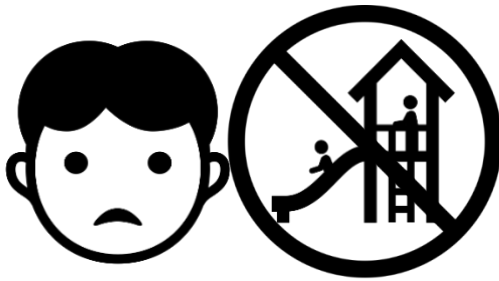
because rules changed quickly.

Even going shopping made

people anxious.



During lockdown, people missed being able to go outside. They could not go out when they wanted to.



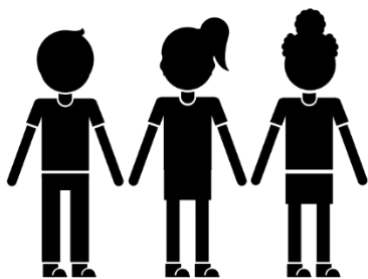
One parent said, it was very hard “when they closed down playgrounds”.



During lockdown, people could not see their family and friends as much as they wanted.



One autistic adult said, “not being able to see anyone has been really hard”. They said, “I cannot deal with being isolated like this. I just want to hug someone”.



Many young people missed their friends. They felt lonely. One young autistic person said, “I really want to see... my friends. In person”.

From the project we have 5 recommendations:



1. The government needs to have better emergency planning. Their planning should include autistic people.



2. Schools and workplaces should have flexible timetables and spaces to learn and work.



3. Telephone or video call health services need to be better. Autistic people should be invited to help design them.



4. Autistic students need to be able to talk to and rely on their teachers even when learning from home.



5. Friendships and community ties are very important. The government should have a plan to help autistic people to keep them during and after lockdown.



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