

“I want to see my friends”

The everyday experiences of autistic people and their families during COVID-19



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Executive Summary

Despite all the talk of being “in it together”, the COVID-19 pandemic and the resulting lockdowns have had dramatically varied effects on different communities across Australia and the world.

This report is the first major investigation into the impact on autistic people and their families.

The report draws on in-depth interviews with 131 people over 115 hours, conducted by both autistic and non-autistic researchers.

It reveals that while many autistic people welcomed enhanced financial support from the government, the increased accessibility of some health and educational services and the slowing down of pressurised routines, they nonetheless felt worryingly unsupported during the pandemic.

In particular, interviewees reported that they found government messages conflicting and confusing, efforts to move therapies and other health support online unsatisfactory and individualised support for schooling from home lacking.

Most strikingly, and in contrast to what might have been expected by some autism researchers, interviewees also emphasised the difficulties brought by the social isolation that followed from strict lockdown requirements. Young people and adults alike spoke movingly of missing friends and of the challenges generated by the absence of broader, more incidental, forms of social connection. Many mentioned the detrimental impact that such disconnection had on their mental health.

Drawing these themes together, the report makes a series of key conclusions intended to influence on-going policy responses to the COVID-19 pandemic. These include:

- 1. Preparation is vital:** All levels of government need to invest in their emergency planning and have a distinct strategy for supporting potentially vulnerable groups, including autistic people. Such a strategy would be considerably stronger if it involved autistic people themselves in its design.
- 2. Flexibility, time and reflective space matter:** The best of the COVID-19 experience was the opportunity to spend more time at home, often with family. This released autistic people from the pressures of everyday timetabling and expectations and was warmly received by many. There is more that could be done to enable autistic people to enjoy these opportunities during more “normal” times.
- 3. Technology is not a stand-alone healthcare solution:** Existing, face-to-face support structures are critical for the wellbeing of autistic people and must not be closed down again if at all possible without adequate alternatives being put in place. Continuity of care is vitally important to autistic people and their families, as are the social contacts and relationships that often come from service delivery.

- 4. Supports for learning from home need radical improvement:** Many parents reported feeling overwhelmed being responsible for directing their child's learning during this time, particularly if they were juggling other demands such as working from home themselves. Social relationships are crucial to educational wellbeing and strong, trusting connections between teachers and students need to be maintained to enable flexible – and differentiated – learning to be continued.

- 5. Friendship and sociability need conscious support:** Very little formal government effort was made during the first few months of COVID-19 to support autistic people in maintaining friendships and social connections. This was a serious mistake. A national plan for deepening and maintaining social relationships is a clear priority for Australia emerging from the first phase of COVID-19.



Acknowledgements

This report provides an in-depth account of what Australian autistic people and their families' lives were like during the first phase of the COVID-19 pandemic. We are extraordinarily grateful to all of our participants for so generously sharing their experiences – the good and the bad. We feel very privileged to have heard them. We have done our very best to convey these experiences as accurately as possible. Any omissions or errors are entirely our own.

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A note on terminology

In the autistic community, identity-first language, e.g., “autistic person”, is often preferred to, and considered less stigmatizing than, person-first language, e.g., “person with autism”. We therefore use identity-first language throughout this Report, unless participants themselves have used person-first language, which we retain in their quotes.

Acronyms

ACT: Australian Capital Territory
ADHD: Attention Deficit Hyperactivity Disorder
COVID-19: coronavirus disease of 2019
NDIS: National Disability Insurance Scheme
NSW: New South Wales
OCD: Obsessive Compulsive Disorder
ODD: Oppositional Defiant Disorder
PTSD: Post Traumatic Stress Disorder
QLD: Queensland
SA: South Australia
TAFE: Technical and Further Education
TAS: Tasmania
VIC: Victoria
WA: Western Australia

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Introduction

2020 has been a year like no other in Australia. Beginning with catastrophic bushfires, the country was then engulfed in its late summer by the COVID-19 pandemic. Most Australians were required to stay home unless engaging in “essential” activities. Schools moved online. Restaurants, bars, theatres and museums closed. People were told to work from home. Socialising with family and friends was halted.

These restrictions, which are on-going in some places as we write, have been very hard on many. Evidence from around the world indicates that people have suffered extraordinary stresses and pressures. Many people’s mental health has suffered. Initial research suggests that the cost to wellbeing has been particularly high for those who were already vulnerable in some way, for example through living with pre-existing mental health conditions or through working at the lower paid end of the labour market.

There is good reason to suspect that autistic people, and especially young autistic people, would have found this period particularly difficult. Previous evidence suggests that many autistic people faced severe challenges to their wellbeing before the pandemic hit. Autistic people also frequently require additional services and supports within the education and health sectors – services and supports which the pandemic placed under threat. Furthermore, autistic people are often thought to be uncomfortable with swift and unexpected change, and to struggle with future uncertainty.

Some autistic people, however, as well as those who work with and support the autistic community, have spoken more positively about the COVID-19 lockdown.

These more optimistic voices contend that several of the service delivery adaptations of this period, such as moving schools, work and therapies swiftly online, as occurred in March 2020, have actually served autistic people well. Some also argue that autistic people may be more adept at dealing with social distancing than non-autistic people, as they can find conventional social interactions unsettling.

The research behind this report set out to discover whether the experiences of Australian autistic people and their families are consistent with these claims. In particular, we asked:

How did autistic children, young people, adults and their families experience the early months of the COVID-19 pandemic?

What did they make of the new online service provisions, in health and education?

What opportunities, if any, did social distancing rules provide?

And what lessons, if any, do we all need to learn from the experience so that we are better prepared if lockdown is needed again?

Methods

This report is the result of an ambitious piece of research, conducted at a time when autistic people all around the world were experiencing the huge disruption that comes from COVID-19.

Our research team – a collaboration between autistic and non-autistic researchers – wanted to gain a fuller sense of what this moment was really like for autistic people and their families. We wanted to understand how different people respond in uncertain times and, in particular, what support autistic people and their families might need.

In order to achieve this, on the 6th May 2020, we posted on social media inviting autistic adults, parents of autistic children and young autistic people to take part in a 45-60 minute in-depth interview about their everyday experiences of life during the COVID-19 pandemic.

Within the space of one month, we had detailed conversations with 131 people¹, including 35 autistic adults, 80 parents of autistic children (including 35 autistic parents of autistic children) and 16 young autistic people aged between 12 and 18 years.

Our participants also came from a wide range of backgrounds and faced a number of very different challenges.

A significant proportion of adult participants were in paid employment prior to the pandemic, although 40% were not. 20% of those who did have a job before COVID-19 saw some kind of change to their employment when the pandemic hit.

People also reported that they or their children had multiple neurodevelopmental and/or mental health conditions. Almost half mentioned that they lived with anxiety and/or depression. Some people also reported complex and chronic physical illness, although others described being in good health.

Most autistic children, as well as a smaller number of autistic adults, were in receipt of a plan through the National Disability Insurance Scheme (NDIS)², which gave them access to funding for supports and services, including during the lockdown period.

The people with whom we spoke came from many different parts of Australia: 69% were from cities and 31% from inner and outer regional communities. Four percent identified as Aboriginal.

Three quarters of our participants reported that they were following the standard social distancing rules as outlined by state or territory authorities at the time of the interviews. The remaining participants were in stricter self-isolation either because they

¹ This is part of a larger project (not reported on here) which involves interviews from France, New Zealand, the Philippines, Sweden, the United Kingdom and the United States.

² The NDIS, funded by the Australian Government, provides no-fault insurance cover for Australians (<65 years), who are born with or acquire a permanent and significant disability. It provides disability funding for support and services directly to individuals and is designed to give them more choice and control over their care.

had suspected COVID-19 symptoms (2%), were officially considered high risk (12%), or some other reason, including a pre-existing health condition (5%). A small number (5%) were interviewed once lockdown had been eased in their location.

More details of our participants are provided in the Appendix.

People spoke to us, on average, for 55 minutes (range = 15 – 100 mins). During the interviews, participants told us about their day-to-day experiences during the COVID-19 pandemic and the impact that they felt it had had on their lives – on their living, working and learning arrangements, their social relationships, access to services and wellbeing. To make our methods as accessible as possible, people could choose to do the interview in a format that was most comfortable for them, either through web-conferencing (Zoom), over the phone, email, or real-time text-based chat.

We recognise, of course, that not all autistic people are able to participate in a discussion of this kind, and, as such, do not claim that our findings are representative of the autistic population as a whole. Furthermore, we did not interview people from the broader non-autistic community and, as such, do not seek here to compare the autistic experience with the non-autistic experience of COVID-19.

The full dataset is currently undergoing rigorous thematic analysis. Here, we present our initial findings through categories which have been identified after close reading of the interview transcripts by the research team, drawing as heavily as possibly on direct quotations from the participants themselves, reported in double quotation marks (“...”). To preserve their anonymity, all quotations reported in this report are left unattributed.

The research team was led by Liz Pellicano at Macquarie University, and was comprised of Jac den Houting and Simon Brett from Macquarie University, Melanie Heyworth from the autistic-led organisation Reframing Autism, Robyn Steward from the UK’s Wellcome Trust and University College London, Anna Urbanowicz from RMIT University and Iliana Magiati from the University of Western Australia. Jac, Melanie and Robyn are autistic researchers; Liz, Simon, Anna and Iliana are not autistic. The report itself was written together with another non-autistic researcher, Marc Stears, Director of the Sydney Policy Lab at the University of Sydney.

All of our procedures were conducted with the approval of Macquarie University’s Human Research Ethics Committee and the written, informed consent of participants themselves.



Positive experiences during lockdown

Despite the enormous disruptions that lockdown caused, our participants were clear that the experience was not straightforwardly negative.

In fact, many described positive experiences.

Some participants acquired new pets: cats, dogs and goldfish. People also engaged deeply with the things they enjoyed. They played Minecraft and Animal Crossing; started painting watercolours; spent time jumping on the trampoline; and even took up new ways of connecting to others. One young adult began his first romantic relationship.

Some people were also optimistic about these positive changes continuing into the future: “I think that whole finding pleasure and experience in things that are close to home and smaller, and in a lot of ways non-consumerist, that’s been rather nice”, one autistic adult said.

These positive reflections can be further categorised into some key areas, which we discuss below.

Innovations in service provision

In the wake of the COVID-19 pandemic, Australians witnessed unprecedented changes in the ways that they work, learn and access services.

Entire workforces began working from home, school and university students switched to virtual classrooms, and people were able to access GP services, mental health treatments and other services from their homes via telephone or video conferencing – what is known as *telehealth* – in order to promote social distancing and limit the spread of the virus.

Many of our participants reminded us that the disability community have long been campaigning for more accessible arrangements for the way that they work, learn and access services – often to be told that such arrangements were simply impossible. To some, the scale and speed with which these innovations were implemented during COVID-19 demonstrated that “the whole world can work remotely”.

For people with disabilities, who “have been banging on the door for years saying, ‘why can’t I do this at home?’”, seeing companies, schools and service providers rapidly, and seemingly effortlessly, make these accommodations for the masses was bittersweet. Yet our participants often praised the efforts that had been made and were hopeful that “there’ll be some positives that come for our community” from these new arrangements. They wanted people to be “more open to kids doing part-time schooling and part-time at home schooling” and for remote working to continue post COVID-19, “creating opportunities for a lot of autistic and other people that have disabilities, who would thrive and be so much more productive in a home environment”.

As one autistic parent put it:

“The world has shown that all the things we needed, weren’t actually that hard to give. Things became a bit more inclusive – and this proves the world can be. I want to see this continue”.

Direct financial support often improved too. Twenty percent of the adults to whom we spoke reported receiving their main income through government income supports and benefits. Many – though not all³ – of these people had seen an important increase to their welfare payments as a result of the Morrison government’s responses to the coronavirus crisis, including the Coronavirus Supplement⁴.

For these participants, such changes had simply “taken away the money stress”, often significantly improving their lives. An autistic adult described how “it’s the first time in ages I haven’t felt stressed and fearful all the time about losing my income and/or being forced to do things that make me ill”. The increased benefits meant that they were “finally getting a decent living amount to cover my expenses and so that I don’t have to worry about things like food or my bills. Or me thinking, oh, I have to pay an electricity bill, now I have to eat minimal amounts for the next week or two... Yes, I would find it really difficult to go back”.

Flexibility, space and time

In addition to these changes in services and supports, participants also described how the lockdown period gave them space and time to learn, live and rethink their lives.

Participants reported feeling less beholden to the often very regulated and intense schedules of their pre-COVID lives, schedules that autistic people often find difficult. As a result, they felt “less stressed”, “more relaxed”, and more in control of their day-to-day lives.

These sentiments were conveyed most clearly by our young autistic participants. Many described how they simply had more time “and freedom” in their days. Some spoke of how happy they were to not have to commute to school. It was extremely enjoyable “just to wake up and just sit at your computer, not having to catch the bus”: “Because I commute for an hour [to school], hour back, you get a lot more time in your day. And I could go to bed later. I could wake up later. And I felt a lot more freedom in class”.

Although people felt unsettled by the rapid changes to daily routines when lockdown began, they also found reassurance that they had more space and time to pursue their interests and hobbies (at least the ones that were doable during lockdown). These included cooking, gardening, writing, drawing, sewing, cosplay, building LEGO, choir singing, animals, playing Minecraft, Dungeons and Dragons and other online games: “The crafting and creative stuff was really restorative, I think. I’m going to miss it”, one

³ People on the Disability Support Pension and Carer Payment – which represented 10 (9%) of our autistic adult and parent participants – were excluded from the Government’s Coronavirus Supplement.

⁴ The Commonwealth Government’s Coronavirus Supplement is a temporary payment of \$550 per fortnight provided to new and existing eligible income support recipients, including those people who received the following payments: JobSeeker Payment (formerly known as Newstart Allowance), Youth Allowance, Sickness Allowance, ABSTUDY (Living Allowance), Austudy, Parenting Payment, Partner Allowance, Widow Allowance, Farm Household Allowance, and Special Benefit.

adult reported. “I think I’ve redone my nails at least four times in the last two weeks”, said another young participant.

Changes in schooling itself were vital here too. Young autistic people frequently report struggling with the rigid and fast-paced timetables of mainstream schooling. During the initial COVID-19 lockdowns, in contrast, some young people described how their high schools had readjusted their timetables so that they “get an extra five minutes between classes to walk around” and “talk to my family, which is good”. Year 11 and 12 students, who reported having “very, very strained” schedules, the extra time “to just have 5-10 minutes to sit back and stretch and relax” was particularly welcome.

Another parent reported on the switch to less-demanding, more flexible learning-from-home and then later classroom arrangements:

“Realistically, 2-3 school-issued activities a day was the most [child] could do without a lot of pressure, and stress for all. We tried to facilitate additional learning through play and books instead. After the first week, [child] returned to school two days a week. He seemed to emotionally benefit from attending reduced school days, and according to his teachers his behaviour at school had improved significantly due to smaller and quieter classes. School became less stressful for him”.

“It’s much better than actual school”, one young autistic person reported. “I actually get stuff done... it was more flexible. I could get tasks set for the entire week and I would be able to do them at my own time at my own pace, as long they were done by the Friday. I just found that a lot easier than the structured time of 70 minutes for each lesson”.

Another made the same point, emphasising that learning from home “just fits my needs better.” They continued: “It’s more of a relaxed environment and I don’t have to be in a loud place with loud people all the time... The resources are more available. It’s easier to get into the lessons. I can wear literally whatever I want without being judged”.

It is not an exaggeration to say that some young people reported that they felt liberated by their new regimes:

“I can do my own thing and I don’t really have a time limit. It’s, like, you have to get this done because you have to do this, you have to get this done because you have to do this next, and then that, and then that, and then that. Now it’s just, like, do it at your own pace. You do you”.

They also felt that having a more flexible routine had made them “more adaptable to different situations in terms of stress”.

Parents often agreed. They described how, prior to COVID-19, everything was “go, go, go”. They were “knackered” from calendars that were “always full” with school activities and after-school and weekend appointments for their child(ren)’s therapies. As a result, many reported a “state of bliss” during lockdown. They felt “less stressed, and less pressured, and less scheduled”.

Parents reported having time “to slow down and focus more on us, than stuff we have to get done”. They were mindful of the need during learning from home to “take breaks when needed and be more flexible about when we needed to rest or ease up

on expectations”. This less-regulated time had given many parents the opportunity to “see where [child] sat academically” and “which areas he needed more support in”.

They also saw the positive effects in their autistic children. Many reported that their child had “benefitted from being at home – she likes her home and family and feels comfortable here”. Some also felt that their child had become “more responsive, interactive, open and affectionate with us during the course of the lockdown”. Parents of non-speaking autistic children had noted that they had been “thriving”. One parent had “seen a bit more speech happening and more words coming and more communication”, while another said that her son “had started recognising pictures [on his communication device]... and started typing as well. So, it’s from nowhere to somewhere. It’s like a miracle”.

One parent summed this up: “I think it’s just that people are trying to simplify their lives, and that’s what we’re trying to do as well. So, not worry so much about overseas travel or material things, trying to focus more on family time and exercise and gardening and things around the household. And, since we have simplified our lives that has helped us really focus on [child’s] needs”.

It was almost as if there was more time just for “being”, as one autistic adult reported:

“I’ve been in a little bubble of sorts ... I know exactly what’s going to happen, I know how to work the things, I know the usual things. Whereas once I’m out of the bubble, everything is difficult again. This bubble, this COVID-19 bubble for me actually, it’s almost... I wouldn’t call it the ideal world, but it’s got a few pretty good conditions for my day to day”.

Family relationships

Given that participants reported having this greater space for “being”, it was also not surprising that many reported enjoying newfound space and time with family, including pets. Parents told us of the welcome opportunity “to spend more time at home” with children and partners, and children and many young people spoke enthusiastically about the chance to pursue their interests and passions.

One autistic adult spoke of the advantage of partners working from home: “we’ve just had lunch and it’s lovely where he gets to cook and I get to enjoy his cooking, and we just hang out together”. Others spoke of the opportunity to “speak to my family more than normal”, including their grandparents, and concluded that “we’re a stronger family unit” as a result of the experience.

Some parents reported that this “increased family time” led to the “formation of an improved family dynamic”. They reported seeing changes in the way that they “treat each other and look after each other”. Even when they noted that “isolation definitely affected our wellbeing to some degree”, they also recognised that “we are talking a lot more about our feelings with each other”.

This time also enabled parents to focus attention on their children and just to enjoy time with them. One told how “we play hide and seek, we read books together. I feel like we have become closer as a result of spending more time together”.

Young people shared many of these reflections. One reported how “there’s a good side of staying home”, which included “being able to be around your family a lot more” and being able to “play with my brother more”. “It’s kind of nice having them [family] at home.”

Young people and autistic adults also highlighted the importance of their pets during the lockdown period, without whom it would have been “really tough”. They described how nice it was “to just read or pat my bird”, “to be around your dogs”, “snuggling [with my dog] at night and every other time”, and to have their “cat join me in a lot of classes”.

Participants described the positive effects that these pets had on their mental health, as one adult described: “it’s very relaxing watching him [fish] – good for my anxiety”.

In the words of one 13-year-old:

“There are some moments where, if life gets so stressful, I’ll just go and sit in an empty room on the chair next to my cat, and just fall asleep with her on the other chair. I think that’s a lot better. Even though she probably doesn’t understand how I’m feeling as far as I’m aware, it’s very therapeutic just to sit with her and think”.

Social solidarity

Participants also reported the connections they felt to their online and local communities. Some described how “people have become a lot more friendly and open”, that they are “smiling and greeting each other more” as they pass each other on the streets and that they had started to “get to know the people across the road”. They also reported “witnessing lots of acts of kindness in the neighbourhood”. They had “found community again”.

Summing it up, one autistic adult said that they “have a good community here but COVID-19 has made it even stronger”.

This sense of solidarity extended to online communities, where participants reported connecting with parent/autistic Facebook groups. As one autistic adult remarked, “I think I don’t know where I’d be without the autistic community, especially through this, because everyone understands, and whilst everyone’s experiencing it differently, there’s still that common understanding as to how people feel”.

One autistic adult described how:

“We have a Community Aid group on Facebook that if someone doesn’t have anything, that someone might bring their food across or whatever... I’m hoping for the community that we can continue as a whole to look out for each other and make sure we’re doing things to keep safe, be healthy, keep everything growing locally, and supporting a lot of local business”.



Challenges of lockdown

Not all of the experiences of the COVID-19 lockdown period were positive, however. Some autistic people and parents of autistic children reported feeling that there was very little that was positive about it. And even those who were more positive shared a strong sense of profound challenge. In fact, the overwhelming sense from the discussions we have had have been of quite severe difficulties that autistic people and their families faced. As one participant very bluntly put it: “No, this isn’t a holiday for me. It’s been really stressful”.

Economic, social and health anxieties

In common with many non-autistic people during the early period of the COVID-19 pandemic, a number of our participants felt deeply unsettled by what the pandemic meant for society, the economy, and the future. One spoke of feeling as if we are living through a “prolonged disaster event”. While “an earthquake goes away soon enough”, they reported, “this keeps going on”.

Some were openly concerned about their own financial security and the strains that that caused for other parts of their lives. Parents were anxious about being “able to hold things together financially, so that our family has a home and some level of stability”, and the “stress that [the financial worries] have put on my marriage”. Others also worried about how they were going to afford the costs of the many supports necessary for their family: “there is no loading for families dealing with multiple people with multiple diagnoses”. One autistic adult spoke nervously about how she was “running out of money” and couldn’t see herself “being able to generate an income, given we’ve got such huge unemployment – there’s no way I’m going to get a job”.

Young autistic people shared these economic concerns. Many were deeply worried about the “many people who’ve lost their jobs through this crisis” and “whether we’ll be able to financially recover from it”.

People were also concerned for others in their communities who might “have fallen through the gaps this time”. As one autistic parent highlighted:

“I hold grave concerns for already vulnerable members of our community (those with disabilities, mental health concerns, recent migrants, those living in poverty, those impacted by violence, addiction, etc.) who were already not receiving anything even close to sufficient support, and will be the first to suffer even more as a result of the economic fallout of restrictions”.

Our participants were also extremely concerned about “increasing racism due to growing tensions between China and Australia”. As one parent explained, “because I’m of Chinese descent, I’m concerned that my children and I might be targets in the future”. One autistic adult spoke of how “there’s a lot of racism out there” and that she was “not looking forward to it being one of the things that I’ve got to think about again... how to protect myself in a post-COVID world”.

The loss of the everyday

The COVID-19 pandemic has caused unexpected and immediate disruptions to people's day-to-day lives.

While these disruptions have been challenging for everyone, they are particularly distressing for many autistic people, who often struggle to deal with uncertainty. As one autistic adult described: "It's been really crappy... I like being by myself, it's just I like also being able to choose when I'm with other people and have some sense of control over my life and it feels like I don't have control over my schedule. It's up to the government, it's up to everything externally and it's just one of those things where I guess because there's nothing I can do to instill a sense of control over my schedule and over my life. It just feels like everything's chaotic".

Autistic adults reported how stressful it has been to see their everyday routines "completely messed up". People reported that their sleeping had been disrupted and that they "haven't been eating much" – or were eating too much. One young person reported that she had "lost all sense of time because of this. I didn't know what month it was two days ago".

Parents talked of the sharp spike in their children's anxiety as they experienced the loss of the usual routine of going to school, of not being able to go to the park, and to do their usual things – sometimes on top of anxiety about getting the virus itself: "he began to carry hand sanitizer with him everywhere... and now is having severe anxiety to the point he has physical manifestations and is going to be seeing a psychologist starting next week".

Parents also felt that, being unsettled themselves by the uncertainty, they often didn't have the energy "reserves for being able to manage their angsty, trying-to-wake-up, grumpy kids". As one parent told us, "my resiliency has bottomed out".

These issues appear to have been exacerbated for those who had a pre-existing mental health condition – which reflected *almost two thirds* (62%) of the people to whom we spoke. They simply didn't have their usual coping strategies to fall back on: they weren't able to take their children to spend time with their grandparents to make it "a little easier on me"; they were unable to "go out and have coffee and be able to have friends come over"; they found it difficult to get rid of their child's "extra energy" outside. They also weren't able to enact their regular forms of "self-soothing, being able to remove myself and come back and feel a bit calmer when I come back... instead, I wasn't able to get out of the space".

As one autistic adult explained:

"I used to go out to some of the islands because it's so beautiful and so relaxing out there. And then they just only allowed the locals to stay there. I understand the logic behind it, but it was kind of like this is my way of escaping things and my method of self-care. So, a lot of my coping strategies have changed. I couldn't do much, the internet's crappy

5 74% (n=26) of autistic adults, 71% (n=25) of autistic parents, 44% (n=20) of non-autistic parents, and 62% (n=10) of young autistic people reporting being previously diagnosed with at least one co-occurring mental health condition (see Appendix).

because everyone's using it. So, I couldn't even play video games effectively without getting killed every couple of seconds".

For some of our participants, their own or their children's anxiety or depression escalated during lockdown to the point that they "restarted antidepressants" and/or re-engaged with their psychologist or psychiatrist. Some had "found it harder to access services such as Beyond Blue, Lifeline. I'd have to call a couple of times. You just end up on hold forever. So I would just give up".

Even more disturbingly, some were experiencing panic attacks, were self-harming and/or talking about suicide. In a minority of cases, participants or their family members – including young people – were admitted to hospital for acute psychiatric care for attempted suicide or severe mental health distress.

"[Child] has fared the worst due to COVID changes. They need to be able to get out of the house at least once a day. They find the home environment stressful – noisy, not often tidy, other anxious people. School helps them to stay on track. When we moved toward lockdown, they were starting to struggle to get schoolwork complete and attend school. They were also talking about suicide. This worsened as they withdrew to their room and we could no longer convince them to go out. [Child] continued to spiral, not leaving their bed for weeks and culminating in an attempted overdose. They eventually went into hospital for further assessment. We were fortunate that both the psychologist and psychiatrist continued to see clients in person as [child] refused to speak on the phone (all my kids hate doing this, as do I – too tiring)."

The trouble with telehealth and learning from home

On the 29th March 2020, the Morrison Government announced a \$1.1 billion coronavirus program to enable people to see or speak to their GP, mental health and other providers for diagnosis or treatment via computer or smart-phone devices without having to leave their homes.

While telehealth has long been used to reach people in Australia's rural and remote communities that have limited access to healthcare, during the COVID-19 pandemic telehealth services have reportedly been delivered to millions of patients all across the country.

Some of our participants were positive about telehealth services. They felt that it was "quite an easy transition to telehealth" and that it has "actually been better". For those that felt either that telehealth was "fantastic" or was "just about the same [as face-to-face sessions]", this meant that they could continue their therapeutic sessions – including psychology, psychiatry, counselling, occupational therapy, speech therapy, and behavioural therapy – during the COVID-19 lockdown period.

But praise for telehealth was far from universal. Many participants – autistic adults, autistic parents, autistic children and young people – also reported negative experiences with regard to telehealth. Indeed, they spoke about deciding either not to access telehealth services, or to begin accessing them and then stopping them altogether as a result of their experience.

Ultimately, this meant that many of our participants stopped receiving therapeutic services during the COVID-19 pandemic.

This apparent lack of uptake of telehealth services may be initially surprising. It has often previously been thought that one of the key barriers to uptake for telehealth services is *clinician* – rather than patient – unwillingness to implement telehealth. Clinician unwillingness was not the cause of the poor uptake in this instance. Although some people reported that their therapists were not offering telehealth during the lockdown period (“my counsellor wouldn’t even call me back”), most told us that their therapists had switched to online services, with the exception of some occupational therapy and physiotherapy services because “they’re both very physical things”.

A further common perception is that autistic people prefer online interactions, because they can often reduce the emotional, social and time pressures experienced in face-to-face interactions. In this case, then, it would have been reasonable to expect autistic people to have embraced telehealth.

But this is not what we found.

Young people consistently reported negative experiences with telehealth. One young man said that while “I’m still seeing my OT, doing it via Zoom... I prefer doing it face-to-face”. Young people talked about how online therapy sessions meant that they “can get interrupted more, because, like, if someone walked in through the door”.

One young person – who was eventually admitted to hospital during lockdown for mental health issues – also described how they had:

“stopped all my psychologist appointments, which was a bad call... because if it’s an online version of a medical appointment of any sort, I just dread it. And the dread is often worse than not doing the appointment – part of not being in person, also because when I’m at home, people can hear”.

One young person summed it up: “Just the idea of talking over Zoom and stuff is not the same as a real person”.

For parents of young children, who had switched to telehealth to continue therapy sessions during lockdown, they too reported negative experiences. Their children “struggled to engage”, would “engage for the first part of it, and then he’d just be over it and wander off”, “would get himself so upset”, or it would “send him into overload”. One parent of a non-speaking autistic child told us: “Telehealth is something that you wouldn’t consider at all from my perspective. It wouldn’t work for our kids.”

With “children’s frequent attempts to leave the session”, some parents were able to talk through things with the therapist themselves, which they found “tremendously beneficial”, gaining some guidance and strategies about how to support their children during this time. For the most part, however, they felt that “progress in the sessions was very limited”, which was “really stressful”. One parent said, “part of me just came to accept that, probably, he wasn’t going to progress very much with therapy in that time”.

For some young children, familiarity and well-established prior relationship was key: “He’d been doing speech therapy in preschool, so last year as well. So, I think he had a good relationship, and he understands what the session involves”. Even established

relationships with therapists, however, didn't ensure engagement: "the speech therapist came into kindergarten and he knows that's a time where you just sit down and you work with that therapist one-on-one, but it just didn't translate to the computer screen".

Parents of teenagers reported that their children simply "refused to do any therapies online" during COVID-19 because "it makes him feel uncomfortable", they had an "aversion to Zoom", or that "she just kept walking away... it was pointless".

Fortunately, some children experienced continuity of care because "his psychiatrist was able to continue face-to-face (to accommodate her largely autistic clientele, many of whom did not want to use telehealth)". For the majority, however, it meant that their children were "not able to get these services currently. We just have to ride it out, so to speak". Many parents therefore described how it was "just a massive, massive relief to be able to begin [face-to-face sessions] again" and, for those who had resumed such sessions, their children were "liking this more and participating more".

It was not only children and young people who found telehealth so challenging. Autistic adults also reported that their psychologist, psychiatrist and counselling sessions had all switched to online or over the phone – and that it did have its benefits: "It's saved me time. It's saved me the stress of going outside and waiting in the waiting room, and all those types of things. So that I could concentrate on my appointment, and focus more, and be less anxious". But adults also found it "really hard", "because of the little delays of online communication", or "not being willing to be having those kinds of conversations having my kids home 24/7".

Ultimately, autistic adults felt that their sessions have "to be face-to-face... I need that personal interaction". They described that "it's more of an interaction rather than just talking to them and just seeing them. Being there is a pretty big part for me, pretty big part of it". One autistic adult explained further that, "with phone calls in particular, because it's taking away the physical aspect and the social section of that, whereas with people with autism, it's hard to socialise as it is. For me, I find that I'm struggling more to communicate with people because I misinterpret things via the phone that I wouldn't misinterpret if I had seen the person's facial expression".

These messages were similar when it came to the technological innovations used to support schooling from home. Although there was much positivity about the flexibility that learning from home provided, as described above, there was also a strong sense that there was not enough of a direct "human" feel to the efforts.

One young autistic person reported, with Zoom, "I don't feel like teachers are explaining the material as well I suppose". Another reported that teachers "are often available but over Zoom, they'll be talking and it's not very good to interrupt them and in real life you can just raise your hand and wait for however long, but they can't really see you over Zoom".

Another young person, studying in his final year of high school (Year 12), felt the same: "Honestly, it was a bit of a mess. The original plan was that they were going to basically have synchronous learning periods. So, essentially that we'll have daily calls or using Microsoft Teams during the periods when we'll usually have those lessons. But some teachers decided not to go ahead with lessons at all, and just gave us worksheets to do and all that. It got a bit confusing at times".

Parents had the same experience. One explained:

“I don’t think the teachers have been individualizing content maybe as much as they would if they were with him, so a lot of it hasn’t been appropriate to his developmental level... it’s across three platforms also, which is kind of confusing to have all these different places that have work and it just would be more screen time for him... and with Zoom, that was not super successful for us, so it was hard for him to focus on Zoom, he’s not that engaged in video calls”.

Others reported that they believed that “no thought” had been put into any of the schooling from home plans. “The teacher did videos to explain work”, this parent continued, “however, he was having meltdowns because the teacher wasn’t responding to him watching the videos. She was not explaining things in depth enough for him and he was consistently confused and stressed out. I had to stop putting the videos on for him and reduce the workload, because it was causing intense stress and anxiety”.

Another parent explained that “[child’s] ordinary challenges that he faced at school increased with needing to do everything via technology with minimal contact. Not having support from his Education Assistant also didn’t help”. In the few instances where extra support was provided, it was sometimes felt, including by young people, to be “not at all useful”.

Lack of clarity in messages

In times of crisis like the COVID-19 pandemic, people look for certainty. People look for reliable instructions about how to protect themselves and their loved ones. For autistic people, who often have a particular affinity for rules and details, this may be especially true. In the wake of the coronavirus, our participants felt that the advice from the Australian federal and state governments “wasn’t communicated as well as it could be”.

They reported trying to gather as much information as they could about COVID-19 and the government’s response to it, in an attempt to reduce the uncertainty – but “accessing information and the right kind of information was overwhelming”. “How quickly everything was changing”, and the fact that “every single state’s doing something completely different”, exacerbated the problem.

Autistic adults struggled with what they saw as the ever-changing rules: “it’s been a bit more anxiety provoking doing things like going to the shops. Because the rules about what social distancing looks like and hygiene stuff looks like can change between one time you go to the shop and the next time you go to the shop. And it’s not always super clear”. They also found it difficult “watching people who did the wrong thing”.

Such uncertainty only served to increase people’s anxiety. As one autistic adult told us, “Before we went into lockdown, I was checking the news a minimum of five times a day. I was put on sleeping tablets by my doctor because I was so wound up and anxious... I didn’t want to go to sleep because I was like, something’s going to pop up, something’s going to pop up, there’s going to be a new update or something bad is going to happen. And then I just had to work through to the point where I wasn’t checking the news as much. And it’s actually around the same time that I got my cat”.

One parent also described her child's difficulties even once the lockdown restrictions had begun to ease: "[Child] finds it a little more difficult, because the social rules are always changing and he doesn't know when they will change again. He said it causes him a lot of stress, because they are meant to stay apart 1.5m in class, but in the playground are encouraged to play tag, contact sports, etc. He is struggling with how inconsistent the rules are and how fast they change".

Parents also described how services – especially schools – didn't always implement government policy as they thought they ought to. One parent, a social worker employed in a health service, recounted a situation with her son's school. Because she and her husband were both deemed essential workers, she had sent her 11-year-old off to school:

"But he was told by his teacher that he would not be at school, and he did not need to be at school. He was asked what I did for a job, and he was told that social workers aren't essential and that he would be staying home with me... he came home really distressed... The principal rang me and even she was like, 'I don't see why he can't stay home', and it's like, with who?"

The confusing messages extended to policies implemented during the COVID-19 pandemic, as one participant explained: "I went into Centrelink a few times trying to find out what I was entitled to and all that. And at the moment they tend to be not able to sit you down and actually explain it all to you. You can't find the website. And all the legal details that you want to know, you can't get past that desk so you can actually talk to someone. So that's frustrating and hard".

While many participants in the NDIS had reported that they had seen no changes to their or their child's packages, they also found "the sheer amount of bureaucracy and inconsistency and mixed messaging and stuff" very challenging to deal with: "apparently everyone with an NDIS plan was meant to be given a priority assistance code for the supermarkets. I got sent an email saying that everyone with an NDIS plan would get priority access, and we'd email you and contact you and there would be no question about how to access the system. I still haven't received any of that contact from the NDIS. Those sorts of things that were advertised as, we're here to support you, and still haven't materialised, months later".

People were also worried about the impact of the COVID-19 pandemic on the future of their NDIS packages. One parent explained, "I manage two really complex NDIS plans, and that's self-managed... there's a lot. It's like a full-time job... I'm aware under COVID we have hardly spent any of our NDIS funding and hardly done any of the goal stuff. That's got to happen, otherwise [child] will lose NDIS funding that they need because we haven't used it".

As one parent put it: "The reality of NDIS is spend it or lose it."

Missing friends and activities

Having to stay at home during the COVID-19 pandemic has been difficult for everyone. But there were some reports in the news and on social media claiming that staying at home and self-isolating was the ideal scenario for autistic people. After all, as one autistic adult described sarcastically, “we self-isolate, we do that all our lives... autistic people are ready”.

Some of our participants (and their children) did indeed “love self-isolation”. They felt “more relaxed” in part because “there’s been no social pressures”. In the words of one young person, “for once, my parents can’t drag me out to places that I don’t want to go!” It also gave people “a bit more control” over their time and who they chose to spend their time with.

Our participants, however, often felt “frustrated”, “stressed” and “sometimes a bit sad” as a result of the requirement to stay at home. There were two key reasons for this distress.

First, the requirement to stay at home other than for essential activities meant that people were unable to go outside as much as or when they would have liked. Contrary to the conventional assumption that autistic people prefer to be on their own indoors on their computers, many people told us how much they missed the outdoors. One young person described himself as having “a lot of energy sometimes”. Parents described their children as “outdoorsy” kids, who “never stop moving”: “We’re on a farm, and he’s in the dirt, in the rain, in the wind collecting things. He’s the kid that you get the iPad and give it to him to try and sit him still”.

One parent described how her child is “very physical and he really, really struggled”. She went on to say that they “made sure that he was getting outdoors because he’d become so scared of even stepping out the front door... but he’s a bouncy kid. We made sure that we were getting him in the backyard, we started doing family walks in the evenings”. Others found that there was “just a lot of anxiety and frustration because it’s really hard to find outlets for his energy and sensory needs”, especially “when they closed down playgrounds”. One parent described how her son “got very frustrated that he couldn’t go anywhere and he got really bored”. The need to stay at home but still satisfy their children’s needs was therefore “challenging”.

It was unsurprising, then, that many parents described the joy they and their children felt when playgrounds opened up, as the restrictions eased: “My daughter has been so happy. The first time I took her back to her favourite playground, she had a huge grin on her face, and she ran around playing on all the equipment”.

Second, people found staying at home challenging because “all the social aspects of my life have been cut out”. Some autistic adults were visibly distressed by this aspect of lockdown: “Just not being able to see anyone has been really hard... I can’t deal with being isolated like this. I just want to hug someone”. This was even the case for autistic adults who very clearly stated, “I don’t need a lot of human contact. Because my anxiety has been quite high, I’ve been a little more needy and I don’t like that about the situation or about myself. It’s something I’ve struggled with. I don’t do being needy well, but I have been really needing a lot more contact from my friends than I perhaps usually would”.

Participants felt that it was “the taking the control away from us, that has been hard”. As one autistic adult described, “I like my quiet time and I like my space, but then at the same time I like social interactions that are face-to-face... where I can control when they happen”.

In contrast to the orthodox view of autistic people as not caring about friendships as much as others, our young participants talked about how they continued to keep in touch with their friends during lockdown – through texting, Instagram, videochat, and online games. But they were resoundingly clear about the extent to which they missed the face-to-face interactions with their friends: “My friends, I really want to see them. I want to see my friends. In person”.

One young person spoke about missing her best friend in more depth:

“I prefer hanging out with him in person as opposed to just over text, so I haven’t been talking to him as much as I do but still somewhat... I’ve really missed that... It’s rare that I find somebody that I actually talk to and in the first five minutes I’m like, oh yes, I know everything about you because you’re me with different interests. It’s rare that I find someone like that. When I do, you got to treasure that”.

Young people often reported feeling lonely: “It’s not that I was ever alone. I always had at least one person in the house with me, that wasn’t the problem. And I love my family, but I was missing my friends”. Another young person described that “the loneliest time was these last few weeks, because my friend got in trouble with her parents for talking to me too much and not doing enough schoolwork”.

As a result, young people were unanimous in what they were looking forward to in life after COVID-19 lockdown: “Seeing people. Obviously. I think that’s pretty much the answer to you that everyone would say”.

Parents also described how much their children “craved” their friends. Some parents described how their children had started to engage with their friends in ways that they hadn’t done prior to lockdown: “Normally when they play together, they run around screaming or [child] hides. But he started to call his friends through Messenger Kids on the iPad and they talk while playing Minecraft. It has been lovely to listen to them interact as they use manners and ask questions and help each other out during the game... and now he’s constantly wanting to chat with his friends”. Another parent told us that for her child to be “texting with her friends and stuff or gaming with her friends... is quite a big deal”.

In their conversations with parents during the lockdown, some autistic children were “mentioning his friends a lot more” or were “always asking when she could play with her friends”. Some children showed that they missed their friends in other ways:

“He doesn’t have a kind of communication where he tells us that he misses them, he doesn’t verbalize that kind of detail, and if we ask the question, he doesn’t respond to questions. But sometimes he talks about his friends while he’s playing with little figurines. He’ll call the little figure the name of one of his school friends, so that might indicate that they’re on his mind... and that he probably misses them”.

Our participants noted that the online connections simply weren't enough. One young person said: "I can't meet many people, and sometimes doing everything online is very different to before, different in a bad way". One mother spoke of how her child "stayed in touch with his friends playing online gaming with them. He enjoyed this, however, he felt very disconnected from his friends. We managed to get one of his friends to do face time chats with him, which helped, but he didn't like the way it felt. He felt like he didn't have the interaction at all. He missed being in their presence and really needed that face-to-face, in-person connection".

One autistic adult described a similar, negative experience: "There's one friend that every Friday, we watch the National Theatre at Home production together, which is nice. It's been good, but also Zoom is exhausting. The online stuff is exhausting. When we already can struggle with communication and you lose even more sense of body language and intonation and all that kind of stuff. It's kind of like, it's much better not".

Another person noted, "the whole transferring to Zoom and not actually being in the same space as someone is hard", which for some people meant that "it's actually been harder to connect with friends than I thought". In contrast to assumptions that autistic people may cope well with, or even enjoy social isolation, then, our participants overall made it clear that this was not the case.

Missing broader social contact

For some participants, the desire for social contact went further than missing their established social circles and quality friendships. Not having much – or in some cases, any – social contact during the COVID-19 lockdown period made them long for it: "I didn't realise how much I actually need human interaction and how much humans actually are somewhat a valuable component of my life". Another autistic adult explained, "Just the lack of it, all those little things. Just interacting and talking about little things like the weather and pals. Someone to keep the time of day, how they went and all those sorts of personal conversations have gone for me. I'm not getting any of that at all".

As another adult put it:

"I didn't realise how important that incidental human contact was to me. It was so incidental that it never really registered on my radar until it was gone".

She went on to give an example:

"The paying for the petrol at the service station, as much as it shits me... because I work with an assistance dog right, so everywhere I go, I've got this giant, white, majestic beast next to me. So, the soundtrack of my life is, 'oh my god, it's a dog. It's a beautiful dog. What kind is he? How old is he? What does he do?' And like, that drives me bananas most of the time, and I've actually found myself even missing that".

People also found themselves trying to be more social than they usually would, prior to the COVID-19 lockdown: "I remember saying to someone at some point that I've been probably more chatty than normal, particularly the café up the road, there's a few people who are always there. People that I know from school and from scouts and stuff. I think I was more willing to do the chit chat thing because I knew I wasn't going to be stuck there".

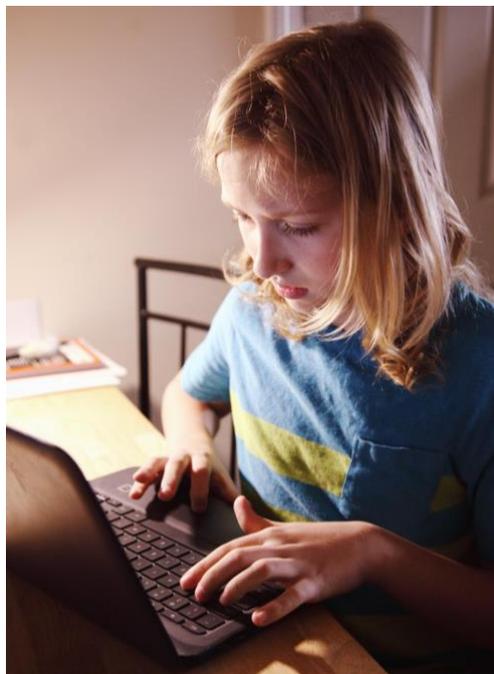
Autistic adults also described how they preferred “being in the office and being around people, and like the security of having those other people around you”, which “makes it feel less lonely”. One adult told us that they were aware that “working from home is something that many people with disabilities have been asking for, for years, but in my experience, that was the biggest barrier for me that made it really hard and led to not being in a good space”. Another adult explained why not seeing colleagues was so difficult for them: “The big disadvantage from working at home is I don’t have that incidental contact with colleagues that just seems to feed my thinking process a bit better, and breaks the day up a bit more”.

Another adult participant recounted how much they “missed getting the train [to work]. I hate getting the train to and from work because it’s an hour and a half each way and peak hour just gets so packed and stuff, but I just miss the routines I had in place and I miss the going into work, seeing people. And that ties into other issues it created with work because of the not being in the same space as people and things”.

Young people also longed for their usual, everyday social experiences: “I’m not sure I like [lockdown] sometimes because I don’t get to see my friends or my family that much. And I don’t get to go to the places I usually go – the library and places like that”. They described looking forward to “bubble tea, stuff like that. Drinks and going to big shopping centres that I don’t really love, but I would enjoy going there now”.

Another young person described that, “as stressful as school was, I don’t really want the form’s social structure to change”. This young man further described how much he missed the regular social contact:

“I think there are some students who at school are just always messing about and do get on my nerves. But now that I think about it, I’m almost longing to just see them running down with a load of lolly packets wanting to sell them to each other... I’ve realised how much I would actually miss them. Mind you it isn’t a lot, but I wasn’t expecting to miss them at all”.



Findings and recommendations

At first sight, this report of the experiences of autistic children, young people and parents might look complex and hard to interpret, with some positives being expressed and other negatives.

There are, however, a number of crucial similarities between the opinions and reflections expressed during these interviews.

On the positive side, many participants reported being glad that the relentless pressures of ordinary life had been lifted during the early months of COVID-19. They felt as if they did not have to conform as straightforwardly to timetables, rules and routines set for and by non-autistic people. They welcomed the initiative that some schools, clinicians and policymakers had taken to create a world within which they could survive – and potentially thrive. They enjoyed the opportunities this afforded them to spend more time with their family members, with their pets, and engaging in their hobbies and interests.

On the negative side, participants most missed those aspects of *social* life that the pandemic lockdown measures took away. They were concerned by the racism and economic anxiety that the pandemic unleashed. Participants struggled with the inability to spend time with friends outside the family, or even to just engage in the incidental social contact that made them feel part of their community. They greatly missed the human contact that typically comes with much service provision and felt that technological innovations like telehealth were an inadequate substitute for face-to-face therapy and support. They felt that the lack of clarity in the messages coming from authorities exacerbated their anxiety. Many reported a decline in their overall sense of wellbeing or mental health.

In our view, these messages lead to five important recommendations for policymakers and others to consider as the COVID-19 crisis continues.

They are:

1. Preparation is vital. The COVID-19 pandemic took policymakers across the world by surprise. This led to uncertainty and an absence of clarity that left many autistic people feeling vulnerable and anxious. In future, clear and consistent information, communicated in accessible ways, will be vital. All levels of government need, therefore, to invest in their emergency planning and have a distinct strategy for supporting potentially vulnerable groups, including autistic people. Such a strategy would be considerably stronger if it involved autistic people themselves in its design. We encourage policymakers at all levels to connect with autistic-led organisations in order for that to be possible.

2. Flexibility, time and reflective space matter. For many participants, the best of the COVID-19 experience was the opportunity to spend more time at home, often with family. This released autistic people from the pressures of everyday timetabling and expectations and was warmly received by many. There is more that could be done to enable autistic people to enjoy these opportunities in more “normal” times. This may include reshaping school timetables to allow for more space between lessons and more opportunities for personal reflection for those who need it. It would be useful as well to investigate possibilities for more flexible arrangements that allow for partial schooling from home for those who find it beneficial and more support for parents who work and school from home simultaneously. These are undoubtedly complex practical challenges. Direct input from autistic people themselves would make such planning more straightforward and likely more effective.

3. Technology is not a straightforward healthcare solution: Existing, face-to-face support structures are critical for the wellbeing of autistic people and must not be closed down again without adequate alternatives being developed. Continuity of care is vitally important to autistic people, as are the social contacts and relationships that come from face-to-face service delivery. Although some participants benefitted from the flexibility and convenience afforded by telehealth, most found that telehealth was not a sufficient alternative to face-to-face service delivery. Existing innovations in technology must not, therefore, be thought of as a panacea for autistic people and significant attention must be played to the relational dynamics of care and support in future. Future deployment of new technologies in healthcare and other social support services should only happen with the involvement of the autistic community.

4. Supports for learning from home need radical improvement: Although some schools made admirable efforts to adjust to the COVID-19 situation, many young autistic people and their families struggled with the technological aspects of delivering and receiving a standard curriculum through hastily constructed online means. This struggle included the lack of appropriate support, and the loss of accommodations and supports provided in mainstream education. Many parents reported feeling overwhelmed being responsible for directing their child’s learning during this time, particularly if they were juggling other demands such as working from home themselves. Social relationships are crucial to educational wellbeing and strong, trusting connections between teachers and students need to be maintained to enable flexible – and differentiated – learning to be continued. These relationships need planned supports, including through taking detailed advice from autistic people and autistic-led organisations.

5. Friendship and sociability needs conscious support: Despite the rhetoric regarding the need to protect mental health, very little formal government effort was made during the first few months of COVID-19 to support autistic people – or other people – in maintaining friendships and social connections. This was a serious mistake, as our participants reveal that social isolation led to many difficulties for autistic people’s wellbeing. In future, more concerted efforts must be made to implement and maintain social support structures for the autistic community, as well as the broader community. Given the likelihood that social distancing will continue for some time, a national plan for deepening and maintaining social relationships during and after COVID-19 along is a

clear priority for Australia. Successful models to investigate can be found in some other countries' national campaigns against loneliness and in more "relational" caring services, including Buurtzorg in the Netherlands.

Each of these recommendations are, of course, demanding, and require much in the way of detailed policy development. Considerations of resource and responsibility are complex, and it is not immediately apparent in each case whether roles should fall to federal, state or local government or to education and health authorities. This requires further policy consideration in the coming weeks and months.

Nonetheless, we believe that each is essential. The experiences of autistic people during the early months of COVID-19 tell us a great deal about the preconditions for thriving and flourishing lives. It falls to all of us to learn those lessons and work to put practical changes in place.



Appendix

Table 1. Background characteristics of our participants.

	Autistic adults ⁶ (n=35)	Parents of autistic children (n=80)		Young people (n=16)
		Autistic parents ⁷ (n=35)	Non-autistic parents (n=45)	
Age in years	M=39.13 (SD=11.41) Range = 23.22 – 69.35	M=42.54 (SD=5.77) Range = 32.80 – 54.48	M=43.26 (SD=8.34) Range = 23.58 – 65.45	M=14.95 (SD=2.08) Range = 12.14 – 18.41
Gender	Woman: n=26 Man: n=7 Non-binary: n=2	Woman: n=33 Man: n=1 Non-binary: n=1	Woman: n=42 Man: n=3 Non-binary: n=0	Girl: n=5 Boy: n=8 Non-binary: n=2 Other: n=1
Place of residence	ACT: n=1 NSW: n=5 QLD: n=4 SA: n=2 TAS: n=2 VIC: n=17 WA: n=3 Prefer not to say: n=1	NSW: n=11 QLD: n=4 SA: n=4 VIC: n=13 WA: n=3	ACT: n=2 NSW: n=21 QLD: n=4 SA: n=2 VIC: n=13 WA: n=3	NSW: n=5 QLD: n=3 SA: n=1 VIC: n=6 WA: n=1
Predominant ethnic Background	Aboriginal: n=2 Chinese: n=1 East Asian: n=1	Mixed (White Australian and Middle Eastern, White Australian	Chinese: n=4 East Asian: n=1	Chinese: n=1 Mixed (White European/Asian): n=1

⁶ Of the 35 autistic adults, the majority (n=32; 91%) had received an independent clinical diagnosis of an autism spectrum condition, while the remaining three adults self-identified as autistic.

⁷ Of these 35 parents, 26 (74%) had received an independent clinical diagnosis of an autism spectrum condition and the remaining nine (26%) self-identified as autistic.

	Mixed (Aboriginal & White European): n=1 White Australian: n=3 White European: n=24 Prefer not to say: n=3	and Hispanic, White European and Asian): n=4 White Australian: n=7 White European: n=24	Mixed (Aboriginal and White European; White Australian and Sri Lankan): n=2 White Australian: n=5 White European: n=29 White Other: n=5	White European: n=12 White Other: n=2
Highest qualification /current school placement	Completed high school: n=4 Vocational educational training/TAFE certificate or diploma: n=9 Undergraduate degree: n=11 Postgraduate degree: n=10 Missing: n=1	Completed primary school: n=1 Completed Year 10: n=1 Completed high school: n=5 Vocational educational training/TAFE certificate or diploma: n=4 Undergraduate degree: n=10 Postgraduate degree: n=14	Completed Year 10: n=2 Completed high school: n=2 Vocational educational training/TAFE certificate or diploma: n=6 Undergraduate degree: n=10 Postgraduate degree: n=25	Mainstream with no extra support: n=4 Mainstream with extra support: n=8 Homeschooling: n=1 Mixed enrolment (mainstream plus online): n=2 TAFE: n=1
Pre-COVID-19 occupational status	Part-time employment: n=9 Full-time employment: n=8 Self-employed: n=4 Studying: n=5 Unable to work due to disability: n=1 Full-time parent: n=2 Unemployed and seeking work: n=4 Retired: n=1 Prefer not to say: n=1	Part-time employment: n=5 Full-time employment: n=8 Self-employed: n=5 Studying: n=2 Unable to work due to disability: n=2 Full-time parent: n=12 Prefer not to say: n=1	Part-time employment: n=14 Full-time employment: n=14 Self-employed: n=3 Studying: n=4 Full-time parent: n=8 Unemployed and seeking work: n=1 Prefer not to say: n=1	

Main source of household income	Salary or wages from employment: n=16 Earnings from self-employment: n=1 Disability support pension: n=2 Age pension: n=1 Government payments (Jobseeker/Jobkeeper, Newstart, Youth Allowance, Parenting Payment, or other income support): n=8 Supported by relatives: n=4 No current income: n=1 Prefer not to say: n=2	Salary or wages from employment: n=24 Earnings from self-employment: n=4 Disability support pension: n=3 Carer payment: n=1 Government payments (Jobseeker/Jobkeeper, Newstart, Youth Allowance, Parenting Payment, or other income support): n=3	Salary or wages from employment: n=37 Earnings from self-employment: n=2 Carer payment: n=4 Government payments (Jobseeker/Jobkeeper, Newstart, Youth Allowance, Parenting Payment, or other income support): n=1 No current income: n=1	
Pre-COVID-19 total household income (AUD)	\$1 to \$25,000 per year (\$1-381/week): n=5 \$25,001 to \$50,000 per year (\$482-962/week): n=14 \$50,001 to \$78,000 per year (\$963-1,500/week): n=1 \$78,001 to \$104,000 per year (\$1,501-2,000/week): n=3 \$104,001 or more per year (>\$2,001/week): n=6 Prefer not to say: n=4	\$1 to \$25,000 per year (\$1-381/week): n=1 \$25,001 to \$50,000 per year (\$482-962/week): n=7 \$50,001 to \$78,000 per year (\$963-1,500/week): n=3 \$78,001 to \$104,000 per year (\$1,501-2,000/week): n=4 \$104,001 or more per year (>\$2,001/week): n=20	\$1 to \$25,000 per year (\$1-381/week): n=1 \$25,001 to \$50,000 per year (\$482-962/week): n=4 \$50,001 to \$78,000 per year (\$963-1,500/week): n=6 \$78,001 to \$104,000 per year (\$1,501-2,000/week): n=8 \$104,001 or more per year (>\$2,001/week): n=18 Prefer not to say: n=7 Don't know/unsure: n=1	

	Don't know/unsure: n=2			
Participant co-occurring developmental, psychiatric and medical conditions	ADHD: n=14 Anxiety disorder: n=22 Autoimmune disorder: n=3 Bipolar disorder: n=5 Chronic fatigue syndrome: n=2 Depression: n=20 Drug/alcohol dependence: n=1 Dyslexia: n=1 Dyspraxia: n=1 Eating disorder: n=5 Epilepsy: n=1 Intellectual disability: n=1 OCD: n=4 Personality disorder: n=3 PTSD: n=10 Sleep disorder: n=9	ADHD: n=13 Anxiety disorder: n=18 Autoimmune disorder: n=9 Bipolar disorder: n=0 Chronic fatigue syndrome: n=1 Depression: n=22 Dyslexia: n=2 Eating disorder: n=3 OCD: n=1 PTSD: n=11 Sleep disorder: n=6	ADHD: n=3 Anxiety disorder: n=12 Autoimmune disorder: n=5 Bipolar disorder: n=1 Depression: n=12 Dyslexia: n=1 Eating disorder: n=2 Personality disorder: n=1 PTSD: n=2 Sleep disorder: n=4	ADHD: n=4 Anxiety disorder: n=9 Depression: n=4 Dyslexia: n=1 Eating disorder: n=2 OCD: n=1 ODD: n=1 Sleep disorder: n=4 Ehlers Danlos Syndrome: n=1
Number of autistic children		n=55	n=56	
Children's age		M=10.37 (SD=4.16) Range = 3.98 – 25.33	M=10.04 (SD=5.44) Range = 3.30 – 29.11	
Children's gender		Girl: n=22 Boy: n=30 Non-binary: n=3	Girl: n=11 Boy: n=42 Non-binary: n=1 Prefer not to say: n=2	

Children's autism diagnoses		Autism spectrum disorder: n=47 Autism or autistic disorder: n=1 Asperger's Syndrome: n=5 Prefer not to say: n=2	Autism spectrum disorder: n=47 Autism or autistic disorder: n=1 Asperger's Syndrome: n=8	
Children's co-occurring diagnoses		None: n=14 ADHD/ADD: n=24 Anxiety disorder: n=29 Cerebral palsy: n=1 Depression: n=3 Dyslexia: n=7 Dyspraxia: n=5 Eating disorder: n=1 Epilepsy: n=1 Intellectual disability: n=1 Tourette syndrome: n=0 Vision impairment: n=1 PTSD: n=2 Sleep disorders: n=6	None: n=10 ADHD/ADD: n=15 Anxiety disorder: n=21 Cerebral palsy: n=0 Depression: n=8 Dyslexia: n=1 Dyspraxia: n=2 Eating disorder: n=5 Epilepsy: n=1 Hearing loss: n=1 Intellectual disability: n=13 Tourette syndrome: n=2 Vision impairment: n=0 PTSD: n=0 Sleep disorders: n=6	
Children's current school setting		Mainstream with no extra support: n=16 Mainstream with extra support: n=21 Autism-specific class within a mainstream school: n=1 General disability class within a mainstream school: n=0 Special school: n=0 Home-schooled: n=5 Other: n=4 Not applicable: n=8	Mainstream with no extra support: n=11 Mainstream with extra support: n=28 Autism-specific class within a mainstream school: n=2 General disability class within a mainstream school: n=3 Special school: n=4 Home-schooled: n=1 Other: n=4 Not applicable: n=3	



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