Autistic Perspectives on Supporting Neurodivergent Children and Families During COVID Times





Autistic reflections on living in lockdown

"It has taken me a long time to process all the changes and transitions that have taken place – my neurotypical friends also struggled with having their routines disrupted, but I think it has given them an insight into what my life was like before Covid."

"Going into lockdown, I realised how much I had been masking in real life, and how much the daily transitions, such as navigating the sensory overload of public transport, were affecting me."

"It was a big relief at first to be able to stop.

Overnight it was like the world accommodated us - all the things the autistic community have wanted and needed for ever, including flexible employment, schooling from home, access to telehealth and different communication options."

Autistic perspectives on supporting autistic students through remote learning

"Remote learning has highlighted something that the neurodivergent community already knew – every student is different, and there is no one size-fits-all. It has highlighted the unique opportunity for our education system to become more flexible."

"As a parent I have taken a 'no expectations' and child-led approach, putting my children's mental health ahead of completing assignments."

"We need to be trauma-informed, and understand that the nervous system can be triggered into a fight/flight by the sensory system. Online learning, with prolonged experiences of sitting in front of a screen may trigger a cumulative threat response for autistic students who need to do hands on stuff to learn."

"As a student, this experience has given me the confidence that I am able to adapt to online learning – we have evidence now that it can work, and can be adapted to suit individual needs."

"Autistic students may need to be able to move, or sit on the floor, or have their camera off so they can fidget off screen we need to normalise these things."

Autistic advice on managing burnout during COVID times

"With the disruption to routines, some autistic people may be less likely to reach out for help during lockdown. It is important to be aware of this, and to check in on a more regular basis with autistic family members, friends or students."

"I have had to process going into lockdown, all the change happened that so quickly. I started understanding what autistic adults meant by experiencing burnout. I experienced a lot of burnout during lockdown – something I had not experienced before."

"I have learnt that I have to manage the sensory overload of Zoom teaching – the importance of scheduling breaks and downtime, rather than trying to push through - having a nap, when I need a nap, as a proactive measure to avoid being wiped out for an entire day."

"When other people were forced to socially retreat, that was actually a time of respite for me. It forced me to take time out for myself, rather than push."

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Coping with Uncertainty in COVID-times

"It is important to be honest and include autistic young people in the conversation - We don't know exactly how long this will go on for, we don't know if and when it will occur again. We can't make promises when we don't know what is going to happen, but we can reassure our kids that we are there to support them."

Creating a Lockdown Plan

One way to manage uncertainty is to create a 'lockdown plan' – a working document, prepared in advance, which outlines what will happen for your family when lockdown occurs. It should be flexible and can customised for each individual, and could include:

Day 1, 2, 3 strategies

It might help your children to know that they are not expected to transition straight into home learning, and may need time to adjust – pyjama days, movies, time with pets. Think what will make the transition more manageable for your family.

A simple and flexible daily schedule, which includes downtime

Think about which routines you need to keep, but also those that might need to be adjusted.

Links to reliable information

Relevant to where you live, on the exemptions/supports available to families with autistic children – eg respite and care arrangements

A parent/carer support plan

How will you access your own supports? What will you do to protect your own mental health/self-care? Do you have a support worker who can come so you can go for a walk on your own? Can you schedule your work in the afternoon to allow for less pressure if you are assisting young ones with home learning during the day.

Incorporating any celebrations that are happening

How can we celebrate in a way that works for our family during lockdown?

Creating a lockdown resource kit

What will we need to be able to work/learn from home? Items could include: pencils, paper, stationary, sensory tools, favorite snacks, games, colouring books, new Lego kits, bath bombs; a gratitude diary; a list of local parks etc.

Creating a Coming Out of Lockdown Plan

Depending on your family's particular needs, this could include:

The plan for returning for school

Whether part time, or full time, or having scheduled days off. Think about what is needed to ensure that your child feels that they are safe.

A flexible schedule for after-school downtime/activities/therapists

Build in lots of downtime, as returning to the classroom is exhausting.

Flexible guidelines around home learning

e.g. school activities 9-11am only, only two subjects a day, school work three days a week and mental health breaks on the other days.

A plan around therapy and support

Does telehealth work? Plan this with your allied health professionals, so you are prepared and know what steps to take when lockdown happens.

Acknowledge where individual family members have conflicting needs

Try scheduling rooms in your house, allocating spaces to ensure each person has some time away from others

Parent/carer permissions

The plan can include permission for parents to be 'not ok' and to be open with their family – 'I need time to recharge by ...'

A list of things to do once out of lockdown

What are we most looking forward to, but also what are we worried about?

Managing the Transition Out of Lockdown

Many autistic children experience school refusal, or 'school can't' when facing the transition from home learning back to school.

"School can't" is not a choice. It is the result of the child's central nervous system going into a threat response. It is the brain's way of communicating 'I feel unsafe."

"There is currently so much for our kids to be anxious about. They need to have that acknowledged and we, as parents/carers/teachers need to be supportive. This is a necessary accommodation – have somebody at school who will talk to your child, or you as a parent before school returns, and answer every single question your child might have. We need a plan for this too."

Information for your child in as much detail as they need

Who is their safe person, what is their safe space, where is their quiet spot, what can they do if they are NOT OK, how can they let the teacher know they are feeling unsafe.