

“I’m the family ringmaster and juggler”: Autistic parents’ experiences of parenting during the COVID-19 pandemic

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Abstract

Background: Little is known about autistic parenthood. The literature that exists suggests that autistic parents can find it difficult to manage the everyday demands of parenting and domestic life. While emerging research has also highlighted more positive parenting experiences, greater understanding of autistic parenthood is needed.

Objectives: This study sought to understand autistic parents' parenting experiences during the initial phase of the COVID-19 pandemic.

Methods: Thirty-five Australian autistic parents (95% women) of autistic children (aged 4 – 25 years) took part in semi-structured interviews designed to elicit their experiences of life during lockdown. We used reflexive, thematic analysis using an inductive (bottom-up) approach to identify patterned meanings within the dataset.

Results: Autistic parents repeatedly spoke of how the lockdown brought some initial relief from the intensity of their usual lives caring for their children. Nevertheless, most autistic parents felt that the “cumulative stress” of trying to juggle everything during lockdown proved very challenging – which eventually took their toll on parents' mental health. Parents were aware they needed support but found it difficult to reach out to their usual social supports (including autistic friends) for help, and formal supports were virtually non-existent. Consequently, they felt “very much forgotten”. Nevertheless, they described how their connections with their children grew stronger over lockdown as they focused on nurturing their children's “mental health ahead of everything else”.

Conclusions: Our analysis shows how challenging conventional life can be for autistic parents. Parenting requires grappling with a distinctive set of demands, which are usually partially manageable through the informal supports many autistic parents draw upon. The relative absence of informal supports during the pandemic, however, left them reliant on more formal supports, which were not forthcoming. Research is urgently needed to identify the most effective formal supports for autistic parents, ideally in partnership with autistic parents themselves.

Community brief

Why is this an important issue?

There is very little research about what autistic parents think about being a parent and how they manage in their everyday lives.

What was the purpose of this study?

We, a group of autistic and non-autistic researchers, worked together to look at autistic people's experiences of life during the COVID-19 pandemic. In this study, led by an autistic parent, we focused on understanding what parenting was like for autistic parents during this time.

What did we do?

We spoke to 35 autistic parents, mostly from Australia, about their experiences of life during the first COVID-19 lockdown. Almost all parents were women. They each spoke to us for about 1 hour. We discussed questions like, "What has been difficult for your child about being required to stay at home? And what has been positive about it? What about you? How have you found having to stay at home?"

What were the results of the study?

Autistic parents told us that life before COVID-19 could "be really hard". Their days were spent focusing on their children and supporting them, but they felt life became a bit simpler during lockdown. They also didn't have "to go out in the non-autistic world", which they found exhausting. But lockdown made things difficult, too. Autistic parents told us they were stressed about trying to juggle everything at home, like home learning, working from home, cleaning the house. They also felt that they were the ones supporting everyone else. This meant they didn't get the rest they needed. They were also worried about COVID-19. These worries and pressure often had a terrible effect on autistic parents' mental health. They wanted to reach out to their friends – especially autistic friends – for help but often couldn't. There were few other supports available to help them. Even when things were difficult, they told us they nonetheless felt

connected with their children during lockdown and that they were putting their children's mental health first, above everything else.

What do these findings add to what was already known?

This study shows how hard everyday life can be for autistic parents. These parents usually rely on their friends for support. But they couldn't do that during lockdown. This meant they had to get help from more official supports and services. But these often just weren't available. As a result, autistic parents felt "very much forgotten" as a group.

What are potential weaknesses in the study?

Most of our participants were women, well-educated and white. We don't know if our autistic parents' experiences would be the same for other autistic parents, like autistic fathers or those from other racial/ethnic backgrounds.

How will these findings help autistic adults now or in the future?

These findings show how important it is to understand how we can support autistic parents and make their lives better during times of crisis and in more normal times. This needs to be done in partnership with autistic parents.

There is a paucity of research on autistic parenthood. For far too long, autistic parents have been deemed “to be very rare” (p. 149).¹ Despite knowing that autism is genetic² and being well aware of the presence of a ‘broader autism phenotype’ in some parents of autistic children,³ even as late as the last decade parenthood was “considered possible” only for a small number of autistic adults (p. 392).⁴ Recently, this perspective has begun to change. The broadening of the diagnostic criteria and subsequent rise in adult diagnoses⁵ mean that few researchers or clinicians would now suggest that autistic parents are rare. Indeed, some parents now report identifying as autistic and/or receiving their own diagnosis after going through the diagnostic process with their own child.⁶⁻⁸ Nonetheless, autistic parenthood remains rarely analysed and poorly understood.

There is reason to expect that autistic parents might find parenthood challenging. The usual logistical demands of raising children – like getting them to school on time, or organising school meetings or playdates – might be particularly taxing for autistic parents, as they may often experience planning and multi-tasking (or ‘executive function’) difficulties.⁹ Autistic adults are also at elevated risk for co-occurring mental health issues, especially depression and anxiety,¹⁰ and the added fear of being stigmatized as a ‘bad’¹¹ or ‘not good enough parent’¹² may have negative effects on their mental health.^{8,13} Some existing research on autistic parents’ experiences has itself served to perpetuate negative and stigmatizing conceptions of autistic parents. For example, some authors have suggested that autistic people’s difficulties with communication and social cognition might make it difficult for them to be emotionally sensitive and responsive to their child’s needs, thus potentially compromising parent-child relationships.¹⁴ Others⁴ have described as “surprising” their finding that autistic and non-autistic parents of autistic children reported similar levels of parenting satisfaction (p. 398), thus feeding into the expectation that “having ASD or autism traits” has the potential to negatively “influence parenting practices and abilities” (p. 2594).¹⁴

The albeit-limited literature also suggests that autistic mothers are more likely to experience prenatal and postnatal depression than non-autistic mothers,⁸ and can find it difficult to manage the everyday demands of parenting and domestic life, including heightened sensory experiences.^{8,11,12,15-16} That said, levels of parenting stress,¹³ parental satisfaction⁴ and perceived self-efficacy in parenting, which can buffer the stress of child rearing,¹⁷ have been found to be *similar* between parents who do and do not identify as autistic. Moreover, and despite reportedly increased parental challenges, recent qualitative research has highlighted the joys of parenthood for autistic mothers, whose narratives revealed an “enduring connection and love” for their children (p. 10)¹² and, when their children are also autistic, a more in-depth understanding of their children’s needs and preferences through sharing an autism diagnosis with them. This shared understanding was echoed by the autistic parents in Crane et al.’s study,⁶ who reported using their own lived experiences to guide discussions with their children about being autistic and fostering a home environment accepting of difference.

In the current study, we sought to understand what parenting was like for autistic parents of autistic children during a particularly unsettling time: the COVID-19 pandemic. During early 2020, UNESCO estimated that more than 90% of children and young people worldwide were required to stay home from school, many without access to playgrounds, sporting or social activities. Many families have faced considerable challenges as they attempt to manage home learning, working from home, financial pressures, and the stress associated with the virus and restrictions deployed to contain it.¹⁸⁻¹⁹ Although there have been some reported positive effects of lockdowns, including a slower pace of life and more family time,²⁰ findings have consistently demonstrated the detrimental impact of the COVID-19-related restrictions on parental stress and mental health, and parent-child dynamics across the population,^{18-19,21-24} particularly for mothers,²⁵ parents with pre-existing mental health conditions,²² and parents who might be vulnerable in some other way, including through social disadvantage, being a single parent and/or caring for a child(ren) with a neurodevelopmental condition.^{24,26}

Many autistic adults have reported a deterioration in mental health during the COVID-19 pandemic,²⁷⁻³⁰ especially women and those with pre-existing mental health condition,^{27,31} as well as a disruption to their usual services and supports.^{28,30,32} Parents of autistic children appear also to have fared badly during the pandemic, especially in terms of challenges to their and their children's mental health and wellbeing,³³⁻³⁷ although rarely is it reported whether the parents themselves are also autistic. In the current study, we drew on data from a large qualitative study examining autistic people and parents' reports of their and their children's experiences of COVID-19 related lockdowns.³⁰ This study showed that the enhanced social isolation accompanying the pandemic had a serious and damaging impact on autistic people's mental health and subjective wellbeing. Here, we focus on the *autistic parents* of autistic children who were interviewed as part of that study. Specifically, we asked: what were autistic parents' experiences of parenting during the first lockdown of the COVID-19 pandemic?

Method

Participants

Our broader study was designed to examine autistic experiences of the COVID-19 pandemic, from the perspectives of autistic adults, parents of autistic children and autistic young people themselves. On the 6th May 2020, we posted a social media advert inviting autistic adults and young adults and parents of autistic children to participate in our study. Eligible participants (n=144) were English speaking; willing and able to convey in-depth their everyday experiences of the COVID-19 pandemic; and, for parents, had a child, of any age, who had received a clinical diagnosis of autism, according to DSM-IV-TR or DSM-5 criteria.³⁸⁻³⁹ These participants were invited to take part in an in-depth interview about their experiences of the COVID-19 pandemic.³⁰

Once we began to schedule interview with parents and speak to them directly, it became apparent that many (n=35) of our parents were autistic themselves. Here, we focus on the 35 participants who identified as being an autistic parent of an autistic child(ren) (see Table 1 for

participant characteristics). These parents reported either having received a formal diagnosis of autism (n=26) in adulthood (M age of diagnosis = 42.92 years, SD=6.63) or self-identified as autistic (n=9). Most autistic parents were white women of moderate-to-high socioeconomic status. Prior to COVID-19, half of our sample (n=18; 51%) were employed, although the occupational status of five of these participants (28%) had changed since the onset of the pandemic. Almost all (94%) reported at least one co-occurring condition, especially depression, anxiety and ADHD. A minority (n=5; 15%) were in receipt of a plan through the National Disability Insurance Scheme (NDIS)ⁱ with autism as their identified disability (three additional parents reported pending applications), which gave them access to funding for disability-related supports and services, including during the lockdown period.

 insert Table 1 about here

With one exception, all autistic parents were interviewed at a time when local stay-at-home orders were in force. Of these 34 parents, 26 (74%) reported staying at home and following the social distancing rules as outlined by government authorities, and seven (20%) reported taking additional measures even though they were not legally required, including self-isolating due to being classified as high risk either due to a pre-existing health condition (n=6; 17%) or suspected COVID-19 symptoms (n=1; 3%) (one preferred not to say; 3%).

Our autistic parent participants were caregivers to, and lived with, 55 autistic children in total, including adult children, ranging in age from 4 to 25 years (see Table 2). Most of their children had at least one co-occurring psychiatric or medical condition (n=41; 74%), most

ⁱ 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. **Those not in receipt of NDIS funding accessed services and supports through other means, including government, charitable and private provision.**

commonly ADHD and anxiety disorder, and most (n=44, 80%) were also in receipt of government support (through the NDIS) with autism as their identified disability.

insert Table 2 about here

Procedures

Ethical approval for this study was received from the Human Research Ethics Committee at Macquarie University (Project ID 6665).

We conducted all interviews between 19th May and 29th June 2020. All participants provided written informed consent prior to taking part.

First, parents were asked to complete a brief (10-minute) online survey, powered by LimeSurvey, to elicit information about their and each of their children's demographic (age, gender, ethnic/racial background, educational, occupational status), diagnostic (autism and/or other co-occurring diagnoses), schooling and COVID-related information.

Next, parents took part in individual, semi-structured interviews over Zoom (n=22, 63%), phone (n=5, 14%) or email (n=8, 23%). We asked participants open-ended questions about their day-to-day experiences of the pandemic and its perceived impact on their living, working and learning arrangements, social relationships, access to services and sense of wellbeing (see Supplementary Materials). We emailed primary questions to participants before the interview to accommodate processing differences.

Zoom/telephone interviews ranged from 21.80 and 86.30 mins (M=56.06, SD=17.80), which were recorded with participants' prior permission before being transcribed verbatim. Prior to analysis, we returned participants' written transcripts to check for accuracy and to remove any potentially identifying or other details.

Data analysis

We followed Braun and Clarke's⁴⁰⁻⁴¹ method for reflexive thematic analysis within an essentialist framework. We identified themes using an inductive (bottom-up) approach to identify patterned meanings within the dataset, involving close reading and re-reading of transcripts. We began the analytic process during the interview phase, with members of the team who had conducted multiple interviews meeting regularly to discuss patterns in the data, including potential codes and analytic 'noticings'. Initially, MH and EP considered directly comparing the parenting experiences of autistic and non-autistic parent participants during COVID-19. Upon extensive reflection and discussion, we felt, however, that this comparative approach might serve to undermine autistic parents' unique experiences by concentrating on differences between parent neurotype rather than on those themes that unified our autistic parents. For this reason – and given that so little attention has been paid to autistic parents specifically – we focused our analysis exclusively on autistic parents. Upon transcription, one senior researcher (EP) took the lead in immersing herself in the data, reading all transcripts twice, taking reflexive notes on striking and recurring observations and applying codes to each transcript (managed in NVivo, version 12). EP discussed the codes and resulting observations with MH and MS at multiple points during this stage of the analysis. EP, MH and MS grouped codes together to identify candidate themes and subthemes. EP then generated a draft thematic map, and the relevant data were collated under each theme and subtheme. The draft analysis was reviewed by and discussed multiple times with MH and MS and then discussed and reviewed with the broader team. Analysis was therefore iterative and reflexive.⁴¹

Community Involvement

This research was co-produced by a team of non-autistic academic partners (EP, SB, IM, MS, & AU) and autistic researchers and advocates (JdH, MH and RS), including an autistic parent of autistic children (MH). All team members actively contributed from the outset of the project, resulting in collaborative decisions regarding methodology, including eligibility criteria, sampling characteristics, the nature and content of each interview, and the procedure itself. Team

members were encouraged to communicate their views at every stage of the process during Zoom meetings, via email and on the various documents. This involvement ensured that autistic people themselves were 'at the centre of the autism conversation',⁴² that our methods were designed to be respectful and supportive of our autistic participants, and the results were interpreted through a strengths-based, rather than deficits-based, lens.

Results

We identified four themes on autistic parents' experiences of parenting during lockdown (see Figure 1; themes and subthemes are also numbered below and presented in bold and italics, respectively). Illustrative quotes are also provided below; participant IDs illustrate the breadth of responses. Note that readers may find some of the issues described below (including self-harm and suicide) distressing.

Theme 1: Regular life “can be really hard at times”

Autistic parents repeatedly spoke of how difficult life was even before COVID-19. They described how “normally, we lead pretty intense lives” (AP217), “a lot of which is about the kids and their activities and supporting them” (AP228), which made them frequently “tired and exhausted” (AP208). As one parent described: “I was a stay-at-home parent and didn't have much time for anything other than caring for my family” (AP211). Consequently, the lockdown initially felt like a *“huge sort of break from reality”* (AP234) (subtheme 1.1). They felt life had become “simpler and easier” (AP211). They enjoyed no longer having to “pack school lunches, get into uniform, make sure you've got the right stuff for the day, work out what was happening after school, who had to go where, who was playing taxi driver” (AP231). As a result, some felt that it was “a welcome breather from regular life” (AP224) and enabled them “to really know what your joys are” (AP208), including “being engaged in school stuff with the kids, which gave me purpose” (AP201), and even “to take care of myself” (AP219).

Parents also reported feeling *an extra release from not “having to go out in the non-autistic world”* (AP226) (subtheme 1.2). As one parent explained: “as an autistic in a non-autistic world, it just

can be so exhausting and draining” (AP205). Instead, they enjoyed “not having to ‘people’, not having to play the game, the usual small talk” (AP234), to be “able to just be ourselves, away from societal pressure and expectations” (AP211). This release included “not having to perform neurotypical parenting so that they don’t think I’m a terrible mother” (AP234), which they felt was “exhausting and tedious” (AP218). One parent explained this “relief”:

Daily interactions for me used to involve some exhausting levels of maskingⁱⁱ, including small talk with parents and teachers at school drop offs and pick-ups for both kids at different schools, running into locals at the shops and the multitude of appointments, kids’ birthday parties, local barbeques... It was suffocating, and COVID restrictions ironically allowed me to breathe for the first time in years (AP210).

Another parent summed up her experience: “We felt a little like people were getting some insight into how we often experience the world: not a place that is really designed for our needs” (AP224).

Theme 2: Lockdown created new pressures

Despite feeling the initial relief from the challenges of pre-COVID life, most autistic parents felt that the “cumulative stress” (AP234) of trying “to juggle all the things and three children and maintain the house and the food and the this and that, and the animals and the pets” (AP219) “proved very challenging” (AP209). As one parent explained, it “created this perfect stress loop... there’s so much stress coming at you from so many places but *“there’s no outlet for de-stressing”* (AP229) (subtheme 2.1). This stress was heightened particularly for working and single mothers and those who had a pre-existing mental health condition (“anyone who is autistic who has a co-diagnosis is so far up shit creek at the moment”; AP204). They described no longer having “any time for silence or calm or anything” (AP218) and missing “having quiet

ⁱⁱ Masking refers to the suppression of autistic characteristics and behaviours in an effort to protect oneself from the potential stigmatisation and judgement of non-autistic people.⁴³

moments to myself on the train to work or going for walks alone” (AP233). Instead, they had “no support and no respite” (AP215) and, as a result, their “nerves had just been frayed from constantly being switched on” (AP209).

Despite the difficulties just “being in survival mode” (AP227), their efforts were focused on “making sure they [the children] are getting through this okay – because that’s what mums do” (AP212). Some reported that their partners “did step up and support me a lot” (AP235) but, for the most part, they felt *it was specifically down to “mum to try to manage it all”* (AP225) (subtheme 2.2). In the words of one autistic mother: “I am the family ringmaster and juggler” (AP207). Some described having to rely more on their partners because parenting was “exhausting – as soon as he comes in the door, I’m just like, ‘they’re yours for at least half an hour, please’. Then, the weekends, I’m just stuffed and basically not able to function” (AP205). Other mothers were frustrated by their partners, who they felt had more free time “just in the shed” (AP226) or “in terms of making trips to the supermarket or going for a ride by himself, or whatever, that has probably kept him balanced without him realising” (AP229). Indeed, one mother lamented: “I have become everybody... it would be really nice to be able to share some of the work with somebody else sometimes” (AP222). Another autistic mother explained:

I feel like my life was put on hold... in terms of other things I had in my mind, the things I might like to explore for myself very much had to be put to the side to actually manage the family and make decisions about what was going to be best for them. And so, once again, mum gets put to the back, doesn’t she?
(AP212)

Consequently, autistic parents found that *more than ever they were “holding everything together for everyone else”* (AP223) (subtheme 2.3). This was especially the case for those with prior executive function difficulties who “already had trouble being organised, and staying on top of chores and family admin, including arranging support for [child]” (AP214) and “all that sort of personal organisation – that’s probably one of the support things I’m missing most” (AP234). They also

spoke of struggling with “the total lack of routine and structure” (AP228) and, while some had managed to instil “some kind of rhythm to the day” (AP221), others could not: “even though I really tried hard to instigate a new routine, because the weekends and the weekdays just blend into each other, I just found that it just wasn’t manageable for me. It was way too much for my executive functioning to cope with” (AP229).

In addition, some reported their home environments to be particularly challenging, including instances of domestic violence and severe mental health distress (including self-harm and suicide attempts) from their children. More often, however, they found lockdown to be “such an intense sensory thing for me” (AP207), especially “the intensity of constantly being in each other’s presence” (AP233). Another parent summed it up:

The sensory overload... We’ve been through school holidays, we’ve been through periods of not having outside support or care, but not ten weeks. Just the sheer amount of noise, the frustration, their not having anyone else to switch onto like a teacher or a carer or whatever. That’s been really hard (AP218).

One parent dealt with this by purchasing “a pair of noise cancelling headphones, which I had always wanted, and, oh my God, that was life changing” (AP212).

On top of this, they were also “*dealing with the heightened anxiety around COVID-19*” (AP211) (subtheme 2.4): “early on, I went through the whole waking up at night, and panic and sweats, and uncertainty and everything” (AP207). They described how they had “placed so much pressure on myself to learn everything I could [about COVID-19] that I slept very little for months on end” (AP230). They reported often spending “a lot of time focussing on the news” (AP201), feeling most stressed around the uncertainty of ““when is this going to end?”” (AP225). They reported how they “like the rules and knowing this is what we’re supposed to be doing” (AP220), but “struggled watching people who did the wrong thing” (AP230) or were “worried I might do the wrong thing... and I didn’t want someone to yell at me” (AP219). This frustration played out most in the supermarket because “no-one was social distancing ... it’s like, ‘can you

take a step back?” (AP202). Some reported having “panic attacks... and a meltdown going to the grocery store” (AP219), and being anxious about “all the panic buying, because every time you went, you’d be like, ‘can we even buy toilet paper’, or ‘can I trust this?’” (AP219).

Parents also reported “not enjoying the ‘vibe’ of other people” (AP224) and that anxiety was infectious, feeling “very affected by other people’s emotions and behaviour and stuff – if I see stress or panic, that makes me feel stressed and panicked” (AP205). They were also mindful that their children “feed off us” (AP218), and that “part of [child’s elevated] anxiety could be that I’ve responded pretty madly myself so that’s probably impacting her as well” (AP213). As one parent put it: “it’s hard to untangle because we’re all dysregulated, and I know we all feed off each other in the wrong direction” (AP204). Hiding their anxiety in front of their children was one way to mitigate the contagion: “I supported my kids by being positive in front of them. If I had shown any anxiety, it would have been a different kettle of fish” (AP230).

Theme 3: “My mental health just tanked” (AP225)

These challenges, including “the level of ambient, continual stress” (AP229), took their toll on autistic parents’ mental health, whose experiences ranged from disrupted sleep, “generalised jumpiness” (AP218) and “inner turmoil” (AP202), to being “extremely stressed, having anxiety attacks, losing my temper a lot, and having suicidal thoughts” (AP214). Others still “began self-harming again as a coping strategy” (AP211). Such challenges appeared to be exacerbated in those who reported pre-existing, co-occurring mental health issues. For some, such challenges felt insurmountable:

At the moment, I have no spoonsⁱⁱⁱ left. When my kids fight, I over-react. I’m anxious about everything. My resilience has bottomed out, and I feel like I can’t make a decision about anything. And I just feel I’ve run out of words every day before I run out of day. So, in all honesty, what was just Monday, was the first day

ⁱⁱⁱ ‘Spoons’ here refers to ‘spoon theory’, an analogy for fatigue and limited resources.⁴⁴

I had a shower in like about two weeks, just because I had been so down and upset. And it's wrapped up in self-loathing and self-worth (AP222).

Parents reported *experiencing extreme states of shutdown, burnout and inertia* (subtheme 3.1).

Some spoke of feeling “like this blob that is totally uninspired” (AP225), “not really having the drive and purpose that I usually have” (AP234). One parent described this in depth:

I entered this rabbit hole that a lot of my autistic friends also told me they were doing, where I had to read everything about COVID. I make jokes that I became a specialist in infectious disease! I read all the papers and all the news, and all the World Health Organisation stuff, constantly. I just put my work aside, and I was still reading at night... So, out of 24 hours I'd say probably about 16 hours of consuming information... And that's really exciting, that puts me into a hyper state, where I just information dump on everyone I know. I could feel it happening. I just rev through and run at a really high rev. And then, the downside of that is at some point my brain just gets exhausted and just stops. And then, there's a big fall off in energy, and motivation, and excitement (AP203).

Others described “having a lot more meltdowns and breakdowns, and not just being able to manage it all” (AP215), and felt frustrated by “watching my friends go, ‘oh, I've crocheted a blanket’, ‘I'm learning Japanese’ ... and I'm going, ‘I'm just surviving. I'm eating, sleeping and raising my child, that's it, that's all I've got headspace for’” (AP220). For others, this led to states of “shut down – sometimes I'll just go to bed and just crawl up in a ball thinking maybe I can sleep because sleep's the easiest way to escape” (AP207) – and inertia: “my procrastination's gone through the roof, but it's more overwhelm. I just have so much I had to do, I just do nothing” (AP235). As another parent described:

And then it just goes, the day just went, I didn't know what day it was. It was just this dead air, this empty space that in some ways was less stress but in other ways

it was more stress, and I wasn't accomplishing, and I wasn't energised, and I just had no purpose (AP228).

Such alterations in time perception were not uncommon: "I just had no sense of the day... I've never felt the clock go so fast, and that really made me feel out of control because I couldn't get everything done no matter how hard I tried. But, at the same time, it's just Groundhog Day – just being the same thing over and over – which is really draining" (AP215). These same parents talked about how this feeling of "not accomplishing eats away at my self-esteem really badly, I feel useless... I just can't get this together" (AP228). Another parent agreed: "you can't do what the school or society expects of you despite the fact that you're trying so hard to keep up" (AP229).

The effects of these often-debilitating states for autistic parents were made worse because they felt *unable to reach out for help* (subtheme 3.2). Seeking help from professionals for their own mental health was felt to be "too hard to even start to talk about it" (AP213), or required "a lot of spare mental space that I just don't have" (AP225). Others talked about feeling ashamed, "like a failure when I have to ask for support" (AP232) to meet everyday needs (like food), their children's needs, or their own parenting-related needs: "[Autism is] an invisible condition and I didn't really feel I could say to the school, look, what you're expecting is overwhelming my executive function skills. I can't do this anymore. It would be seen as a shameful thing... a failure on your part as a parent" (AP229).

While some parents were in contact with "very close dear [autistic] friends... who get me more than anyone else" (AP222), they also described "missing adult interactions" (AP228) and "friends, who are my safety net" (AP219). Some reported withdrawing from their usual social supports during lockdown, many of which involved autistic friends and people online: "when I collapse, I just stop reaching out and talking, and just ride it out" (AP203). Sometimes "removing myself from a lot of social groups" (AP212) was a conscious choice: "I dipped out of the [autistic] community just because I felt that everyone else was panicking and it was causing me to

panic” (AP225). Other times, however, it was circumstantial. While our autistic parents felt supported by and connected to their autistic friends during pre-COVID-19 times, even these informal supports were taken away during COVID-19: “It’s actually been harder to connect with friends than I thought, because so many of my friends are autistic, we’re all in burnout and overload” (AP204). As one parent put it:

I’m now dealing with X number of support coordinators, service providers, social workers, support workers, therapists, and I’m peopled out. I love my friends, desperately love my friends, and desperately love spending time with them, but I just don’t have that capacity on top of everything else that I’m doing (AP207).

Indeed, some mentioned being disappointed that “friends didn’t check in because they assumed that we would be happy to stay at home all the time” (AP230). For others, social withdrawal was related to the severity of their response to lockdown:

[My own wellbeing] it’s shocking, it’s just absolutely shocking ... I have isolated myself further from people because I just don’t want to engage, because I can’t even answer the question when people say, ‘how are you?’ (AP232).

While autistic parents appreciated how much they needed ongoing informal support, many agreed that *formal support was virtually non-existent* (subtheme 3.3). Some parents described not being able to access formal supports at all (“I’m a single mum and I don’t have any other support”; AP217). For others, such supports had disappeared altogether (“all of a sudden, overnight, we lost the support workers”; AP218) or had been severely disrupted, particularly for those accessing psychological services, which had shifted to telehealth (“I can’t do phone appointments. No, no, no. How ineffective would that be?”; AP205). Some had not pursued a formal autism diagnosis “because even if I spent AUD\$1,500 to get a formal diagnosis, it seems like the government is not going to do anything to help me. They’re not going to offer me, from what I can tell anyway, any support” (AP210). Even those with a formal diagnosis were

concerned about “people making assumptions on our capacity and ability” (AP230), especially if they should need help and support during the pandemic:

I wasn't entirely worried about getting [COVID-19] and dying, but I was worried about getting it and ending up in the hospital system... and trying to explain to doctors about being autistic, and just getting that look where they're just like, yes whatever, she's full of shit, or she's just a hypochondriac or a drama queen, all of those typical labels that female autistics get (AP204).

Overall, however, they reported feeling “very much forgotten” (AP229). This same parent went on to explain: “I've had to do so much advocating for [child] over the years, ever since she was a preemie baby, I've been advocating for her from the moment she was born... But no one is advocating for me”.

Theme 4: Distinctive autistic insights supported family life

Autistic parents recognised that they needed “time by myself to reenergise” (AP209) and “more opportunities to do self-care” (AP214) so that they could “better support everyone else” (AP218) – especially their children. Some were aware of the need to go easy on themselves during what was an extraordinary time: “I'd like to think I did my best to just get through it, manage and stuff” (AP218). They were adamant, however, that while “we've got these challenges we need to be more open about, it doesn't mean that we don't love our kids” (AP228). Indeed, during lockdown they reported “*feeling much more connected*” to their children (AP226) (subtheme 4.1), enjoying “kisses all the time” (AP226) and “cuddles all day” (AP206), and “learning with him and finding ways to make it easier for him and more enjoyable for him” (AP211). They described being attuned to their autistic children's way of being (“she always wants to be near me because I guess I get her”; AP209) and able to empathise with their experiences: “[daughter] is quite exhausted from her experience and tires easily. Being autistic, I know what it is to burn out and that it takes time to return to 'normal' life” (AP224). One parent put this (mis)attunement into perspective when describing her neurotypical child's experience of lockdown: “she's probably

found it the hardest, being an extrovert and she's very social... She's probably the most challenging for me as a parent because, yes, we're not wired the same. I just don't understand her at all" (AP205). They also conveyed the importance of a sense of openness in their family conversations, "being very upfront about what each other needs" (AP226), including the need to be "calm and factual" (AP210) about COVID-19: "[Children] are pretty good in that they're very logical too, so giving them the facts of, this is what's happening, this is how we can keep you safe, they understood that" (AP220).

Parents' insight both into their own mental health challenges and their connections to their children's needs seemed to make them *attentive to their children's mental health and wellbeing* (subtheme 4.2), making "a conscious choice to ensure our kids have their mental health intact" (AP212) during lockdown, over and above "the academic side of things" (AP205). This often meant "just giving space and time when needed, not forcing things when it's not warranted and giving a bit of leeway" (AP221). This parent went on to explain:

Having him home has been really good because I love learning... I would sit with him and really spend that time to really remedy a lot of his anxiety around things and focusing on, 'all right, let's get your first fail out. Let's get one answer down that we know is wrong, just get it out. And then we can work out how we stuffed up and move from there'. It's been really good to rebuild his trust in himself (AP221).

For some parents, this also meant that their children focused on their interests and passions ("he got really obsessed with physics"; AP218) and learning life skills, as one parent described:

The first week was us trying to follow what the school sent home but there was nothing engaging to him. So, I was like, we'll go and learn things that are actually important. That's part of the reason why we got chickens, and we also have a huge veggie garden now which we didn't have before. And we taught adaptive

skills: he learnt how to garden, he learnt how to look after chickens, and he learnt how to talk a bit better (AP225).

Parents were also acutely aware of how much their children “really missed their friends” (AP233) and reflected on how much the lockdown “may have impacted quite seriously with those friendships” (AP227). They were therefore especially understanding when their children “got a bit distracted sometimes by chatting with her friends” (AP201): “The older one was mostly either texting with her friends and stuff or gaming with her friends, which is quite a big deal. So, that to me was more important for her to be doing than learning math that she already learned last year” (AP216).

Discussion

This study examined autistic parents’ experiences of parenting during the initial phase of the COVID-19 pandemic. Although the autistic parents who participated in our study felt an initial relief from ordinary life, particularly from having to engage in a world that is not typically set up for them, many nevertheless struggled with managing the additional sensory, domestic and organisational demands that ensued with having to care for their family and themselves during lockdown. In this context, it is not surprising that the mental health impact of this pressure was severe, particularly for autistic parents who were already vulnerable in some way, including those with pre-existing mental health conditions, or who were single mothers. This worryingly manifested as burnout, autistic inertia and acute mental health distress. The absence of formal supports was striking and made evermore apparent when parents’ informal supports – often connections with other autistic parents – were stripped away by lockdown. Through all these challenges, however, our participants carried on, often driven by a deep devotion to their children and families, focusing intensely on nurturing their family’s mental health and wellbeing.

Our analysis clearly illustrates how difficult everyday life can be for autistic parents even in “usual” less challenging times than a pandemic. Autistic adults who are not necessarily parents already face many challenges in different facets of their lives.⁴⁵⁻⁴⁶ They can struggle with executive

function⁹ and report often masking or ‘passing as normal’ in social situations,⁴³ which may in part be a response to perceived stigma⁴⁷ but is nevertheless both effortful and costly, particularly to mental health.⁴⁸⁻⁵⁰ These many challenges, however, may be exacerbated for autistic people who are also parents. Parenting requires grappling with a distinctive set of demands, including juggling and transitioning between multiple commitments (e.g., to and from school pick up, extra-curricular activities, and social outings), anticipating needs, and dealing with different social expectations and obligations, which are often child-related (e.g., organising playdates, communicating and interacting with teachers and other professionals, and other parents). This often-hidden labour is a gendered phenomenon, with women taking on the bulk of the work⁵¹ – as our autistic mothers did, too. Further still, autistic parents report managing these daily demands by masking for their children as well as themselves in interactions with parents and professionals, which may well be doubly damaging for their wellbeing.^{8,12} They are also reluctant to disclose their autistic identity for fear of negative judgments about their parenting skills,^{8,11} which may mean that they are less likely to turn to others for support as a result.⁸ Our participants’ experiences of these everyday challenges prior to the pandemic corroborate these findings.

Autistic parents spoke also of the value they placed in the informal support they received from other parents, especially autistic parents, prior to the pandemic, with whom they enjoyed mutually supportive interactions. Emerging research has demonstrated that autistic people feel at greater ease⁵² and have stronger connections with “other ‘like-minded’ people” (p. 529),⁵³ who are “on the same wavelength” (p. 5)⁵⁴ and offer mutual respect and empathy.⁵⁵ Spending time with other autistic people, especially in autistic spaces,^{42,56} can also engender a sense of belonging.^{53,57} Our findings suggest, contrary to prevailing beliefs of a diminished desire for social connection,^{58, but see 59} autistic parents can and do maintain robust, predominantly autistic, social networks, which can help them to navigate the demands of day-to-day life and overcome the

stigma of autistic parenting. More research is needed to understand how *non-autistic* people might become more effective social supports for autistic people.^{cf 57}

Participants further described, however, that the lockdown restrictions severely impacted their capacity to draw upon these informal supports, partly because they missed face-to-face interactions³⁰ and partly because their autistic friends and supporters were also reportedly suffering in their own ways due to lockdown. The relative absence of informal supports, in turn, left them reliant on more formal supports, many of which were not forthcoming during the pandemic and those which were available (especially via telehealth) were not well-designed to people's needs.^{28,30,32} Supports and services for autistic adults are already extremely limited, even in pre-COVID times,⁶¹⁻⁶³ despite autistic people reporting a significantly higher number of unmet support needs than the general population.⁶⁴ Most of our participants reported additional co-occurring physical and mental health conditions (like many autistic adults^{10,65-66}), and while many received government-funded formal support for their autistic children (through the NDIS), relatively few received such support for themselves.

For those who were in receipt of formal support prior to the pandemic, this support often disappeared during the lockdown restrictions because, for example, support workers were prevented from entering people's homes or because there was disruption to the usual (face-to-face) therapeutic services.^{28,30,32} Further still, our autistic parents, including those who were experiencing mental health distress, felt unable to reach out for help.⁸ This may have exacerbated their situation even further, but, as our participants highlighted, support for autistic parents – who felt their experiences were unique and required knowledgeable and targeted care – remained virtually non-existent. Research is therefore urgently needed, in partnership with autistic parents themselves, to understand what kinds of formal supports would be most well received by autistic parents to relieve some of their everyday challenges in more normal times.

One area on which additional focus could be placed is the development of self-compassion, or the non-judgmental understanding of one's pain and recognition of pain as part

of broader human experiences.⁶⁷ Our participants repeatedly reported low self-worth, and feeling ashamed or embarrassed about their everyday challenges, in part due to actual or anticipated negative judgments about their parenting from others.^{see also 8} Exceedingly little is known about cultivating self-compassion in autistic people, including whether it might have a positive impact on mental health.⁶⁸ Encouragingly, our participants were highly cognisant of the need to practice self-care to ensure their own and their children's wellbeing, and some actively did so despite the lockdown restrictions – and some also recognised the importance of not being too self-critical, especially given the extraordinary circumstances. More formal support in developing and practicing self-compassion might well be one avenue to pursue for autistic parents specifically, especially to reduce such internalised shame.

The combination of the relative absence of formal supports, discontinuity of care and the cumulative stresses of caring for their children and themselves, on top of the uncertainty related to the pandemic itself, appeared to create, in the words of one parent, “a perfect storm” (AP229). Nevertheless, throughout all of this, autistic parents persevered in part because of the strong relationships they had with their children. Many of our participants described that sharing an autistic identity with their children made them feel closer to and more connected with them. They reported being open and transparent in their communication (including about the virus itself), felt that they had an intuitive understanding of their children's often-distinctive needs, and responded flexibly to attend to them. They were also conscious of prioritising their children's wellbeing, especially when they knew that they were particularly vulnerable in this regard. Indeed, some battled through intense mental struggle to do so. These findings of a deep emotional connection with, and love for, their children are consistent with other recent qualitative work with autistic parents,^{6,12} and highlights the potential affordances of experiential expertise and mutual understanding.⁵⁵ More research is needed to understand the short- and long-term benefits of promoting a narrative of difference rather than deficit on the quality of life of children, parents and broader family.¹²

Limitations

This study is not without its limitations. First, our sample was self-selecting in nature, making it possible that those with particularly challenging experiences were more likely to respond to an invitation to take part in our study. That said, our findings, especially of people's accounts of pre-COVID parenting experiences are comparable with existing research. Second, our participants reported themselves to be predominantly well educated and of white background. The debilitating effects of the lockdown restrictions are likely to be an *underestimate* of those experienced by those from more diverse backgrounds, who are 'seldom heard' and likely to be multiply disadvantaged.^{21,69} Third, the overarching research question for our broader study was not explicitly focused on autistic parents. Although the semi-structured nature of the interviews allowed the interviewer to probe about autistic parents' own experiences of the pandemic, and also encouraged participants to tell their experiences in their own way, it is possible that we would have elicited additional or different information had we had a narrower focus. Finally, akin to the existing research,^{8,12} almost all of our participants were mothers. Future research should examine the ways in which autistic men and non-binary parents experience parenthood.

Conclusion

The COVID-19 pandemic has caused profound difficulties for people across the world. It is also widely acknowledged to have impacted people unequally, with the starkest disadvantages often experienced by those who already faced the harshest challenges before the pandemic broke. This phenomenon is displayed once again here in this study. Before the pandemic hit, autistic parents were already confronted with extraordinary challenges in a multitude of settings in everyday life, ranging from the overwhelming conventional expectations that are placed on them by teachers, other parents and broader society, to the absence of formal supports from government or other authorities. These challenges were intensified further still during the pandemic, in part because the informal supports upon which autistic parents often rely to redress

the disadvantages they face became far harder to access or were even entirely withdrawn. Such an experience reminds us how important it will be to do all we can to help autistic parents and their communities maintain those informal supports in any future pandemic or similar scenario. It also reveals how crucial it is to enhance the formal supports available during times of crisis. Most of all, however, it demonstrates the need to shape a world where autistic parents can, as far as possible, be released from the unfair and unrealistic expectations of non-autistic parents and others and be able to thrive along with the children for whom they care so much.

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Authorship confirmation statement

EP conceived of the study and secured funding. EP, SB, JDH, MH, IM, RS, and AU designed the study. EP supervised data collection and analysis. EP, SB, JDH, MH, IM, RS, and AU collected the data. MH, MS and EP led the analysis and interpretation of the data. MH and EP verified the underlying data and wrote the original draft of the manuscript. All authors contributed to reviewing the analysis and editing the manuscript prior to submission.

Authors' disclosure statements

The authors have no competing interests of which we are aware.

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References

1. Ritvo ER, Ritvo R, Freeman BJ, Mason-Brothers A. Clinical characteristics of mild autism in adults. *Comp Psych*. 1994; 35:149 – 156.
2. Folstein S, Rutter M. Genetic influences and infantile autism. *Nature*. 1977;265:726–728.
3. Piven J, Palmer P, Jacobi D, Childress D, Arndt S. Broader autism phenotype: evidence from a family history study of multiple-incidence autism families. *American J Psych*. 1997;154:185 – 190.
4. Lau WYP, Peterson CC. Adults and children with Asperger syndrome: Exploring adult attachment style, marital satisfaction and satisfaction with parenthood. *Res Autism Spectrum Disord*. 2011;5:392-399.
5. Lai M-C, Baron-Cohen S. Identifying the lost generation of adults with autism spectrum conditions. *Lancet Psych*. 2015;2: 1013–27.
6. Crane L, Lui LM, Davies J, Pellicano E. Short Report. Autistic parents' views and experiences of talking about autism with their autistic children. *Autism*. 2021;24:1161-1167.
7. Lilley R, Lawson W, Hall G et al. "Peas in a pod": Oral history reflections on Autistic identity in family and community by late-diagnosed adults. Manuscript in submission.
8. Pohl AL, Crockford SK, Blakemore M, Allison C, Baron-Cohen S. A comparative study of autistic and non-autistic women's experience of motherhood. *Molecular Autism*. 2020;11;3.
9. Demetriou EA, Lampit A, Quintana DS, et al. Autism spectrum disorders: A meta-analysis of executive function. *Molecular Psych*. 2018;23:1198–1204.
10. Lai M-C, Kasseh C, Besney R, et al. Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *Lancet Psych*. 2019;6:P819 – 829.
11. Rogers C, Lephherd L, Ganguly R, Jacob-Rogers S. Perinatal issues for women with high functioning autism spectrum disorder. *Women and Birth*. 2017;30: e89 – e95.

12. Dugdale A-S, Thompson AR, Leedham A, Beail N, Freeth M. Intense connection and love: The experiences of autistic mothers. *Autism*. 2021;25:1973 – 1984.
13. Adams D, Stainsby M, Paynter J. Autistic mothers of autistic children: A preliminary study in an under-researched area. *Autism in Adulthood*. 2021;3:339-346.
14. Dissanayake C, Richdale A, Kolivas N, Pamment L. An exploratory study of autism traits and parenting. *J Autism Dev Disord*. 2020;50:2593 – 2606.
15. Gardner M, Suplee PD, Bloch J, Lecks K. Exploratory study of childbearing experiences of women with Asperger Syndrome. *Nursing for Women's Health*. 2016;20:P28 – 37.
16. Talcer MC, Duffy O, Pedlow K. A qualitative exploration into the sensory experiences of autistic mothers. *J Autism Dev Disord*. In press: <https://doi.org/10.1007/s10803-021-05188-1>
17. Lau WYP, Peterson CC, Attwood T, Garnett MS, Kelly AB. Parents on the autism continuum: Links with parenting efficacy. *Res Autism Spectrum Disord*. 2016;26:57 – 64.
18. Cameron EE, Joyce KM, Delaquis CP, Reynolds K, Protudjer JLP, Roos LE. Maternal psychological distress & mental health service use during the COVID-19 pandemic. *J Affective Disord*. 2020;276:765–774.
19. Patrick SW, Henkhaus LE, Zickafoose JS, et al. Well-being of parents and children during the COVID-19 pandemic: A national survey. *Pediatrics*. 2020;146: e2020016824.
20. Calvano C, Engelke L, Di Bella J, Kindermann J, Renneberg B, Winter SM. Families in the COVID-19 pandemic: parental stress, parent mental health and the occurrence of adverse childhood experiences—results of a representative survey in Germany. *European Child Adolesc Psych*. In press: <https://doi.org/10.1007/s00787-021-01739-0>
21. Creswell C, Shum A, Pearcey S, Skripkauskaitė S, Patalay P, Waite P. Young people's mental health during the COVID-19 pandemic. *Lancet Child Adolesc Health*. In press: [https://doi.org/10.1016/S2352-4642\(21\)00177-2](https://doi.org/10.1016/S2352-4642(21)00177-2)

22. Russell BS, Hutchison M, Tambling R, Tomkunas AJ, Horton AL. Initial challenges of caregiving during COVID-19: Caregiver burden, mental health and the parent-child relationship. *Child Psych & Human Dev.* 2020;51: 671 – 682.
23. Westrupp E, Bennett C, Berkowitz TS, et al. (2020). Child, parent, and family mental health and functioning in Australia during COVID-19: Comparison to pre-pandemic data. Preprint: <https://doi.org/10.31234/osf.io/ydrm9>
24. Whittle S, Bray KO, Lin S, Schwartz O. Parenting and child and adolescent mental health during the COVID-19 pandemic. Preprint: <https://doi.org/10.31234/osf.io/ag2r7>
25. Blanden J, Crawford C, Fumagalli L, Rabe B. *School closures and parents' mental health*. Institute for Social and Economic Research Briefing Note May 2021. 2021. Retrieved from <https://www.iser.essex.ac.uk/files/news/2021/school-closures/school-closures-mental-health.pdf>
26. Sicouri G, March S, Pellicano E, et al. Mental health symptoms in Children and adolescents during COVID-19 in Australia. Manuscript in submission.
27. Adams RE, Zheng S, Taylor JL, Bishop SL. Ten weeks in: COVID-19-related distress in adults with autism spectrum disorder. *Autism.* 2021;25: 2140-2145.
28. Bundy R, Mandy W, Brinkert J, et al. The impact of early stages of COVID-19 on the mental health of autistic adults in the United Kingdom: A longitudinal mixed-methods study. *Autism.* In press: <https://doi.org/10.1177/13623613211065543>
29. Oomen D, Nijhof AD, Wiersema JR. The psychological impact of the COVID-19 pandemic on adults with autism: A survey study across three countries. *Molecular Autism.* 2021;12: Doi:10.1186/s13229-021-00424-y
30. Pellicano E, Brett S, den Houting J, et al. COVID-19, social isolation and the mental health of autistic people and their families: a qualitative study. *Autism.* In press: <https://doi.org/10.1177/13623613211035936>

31. Bal VH, Wilkinson E, White LC, et al. Early pandemic experiences of autistic adults: Predictors of psychological distress. *Autism Res*, 2021;14:1209–1219.
32. Oakley B, Tillmann J, Ruigrok ANV, et al. COVID-19 health and social care access for autistic people and individuals with intellectual disability: A European policy review. *PsyArXiv* [Preprint] Available from 10.31234/osf.io/n6d3f [cited 18 Jan 2021].
33. Asbury K, Fox L, Deniz E, Code A, Toseeb U. How is COVID-19 affecting the mental health of children with Special Educational Needs and Disabilities and their families. *J Autism Dev Disord*. In press: <https://doi.org/10.1007/s10803-020-04577-2>
34. Colizzi M, Sironi E, Antonini F, Ciceri ML, Bovo C, Zocante L. Psychosocial and behavioral impact of COVID-19 in autism spectrum disorder: An online parent survey. *Brain Sci*. 2020;10: 341. <http://dx.doi.org/10.3390/brainsci10060341>
35. Latzer IT, Leitner Y, Karnieli-Miller O. Core experiences of parents of children with autism during the COVID-19 pandemic lockdown. *Autism*. 2021;25: 1047-1059.
36. Lee V, Albaum C, Tablon Modica P, et al. The impact of COVID-19 on the mental health and wellbeing of caregivers of autistic children and youth: A scoping review. *Autism Res*. In press: <https://doi.org/10.1002/aur.2616>
37. Toseeb U, Asbury K, Code A, Fox L, Deniz E. Supporting families with children with special educational needs and disabilities during COVID-19. *PsyArXiv*, <https://psyarxiv.com/tm69k/>
38. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders (4th ed., text rev.)*. Washington, DC: APA; 2000.
39. American Psychiatric Association (APA). *Diagnostic and Statistical Manual of Mental Disorders (5th ed.)*. Washington, DC: APA; 2013.
40. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Research in Psy*. 2016;3:77–101.

41. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Research Sport Exercise Health*. 2019;11:589–97.
42. Ne'eman A. Question and answer interview.
<http://www.talkaboutautism.org.uk/page/liveevents/arineeman.cfm>
43. Pearson A, Rose K. A conceptual analysis of autistic masking: Understanding the narrative of stigma and the illusion of choice. *Autism in Adulthood*, 2020;3:52-60.
44. Miserandino C. The spoon theory. Available at:
<https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>
December 12, 2021.
45. Howlin P. Adults with autism: Changes in understanding since DSM-III. *J Autism Dev Disord*. 2021;51:4291 – 4308.
46. Pellicano E, Hall G, Heyworth M, et al. (2021). Flourishing lives in autistic adulthood: a capabilities approach. Manuscript under review.
47. Perry E, Mandy W, Hull L, Cage E. Understanding Camouflaging as a response to autism-related stigma: A social identity theory approach. *J Autism Dev Disord*. In press:
<https://doi.org/10.1007/s10803-021-04987-w>
48. Bradley L, Shaw R, Baron-Cohen S, Cassidy S. Autistic adults' experiences of camouflaging and its perceived impact on mental health. *Autism in Adulthood*. In press:
<https://doi.org/10.1089/aut.2020.0071>
49. Cage E, Troxell-Whitman Z. Understanding the reasons, contexts and costs of camouflaging for autistic adults. *J Autism Dev Disord*. 2019;49:1899–1911.
50. Hull L, Levy L, Lai M-C, et al. Is social camouflaging associated with anxiety and depression in autistic adults? *Molecular Autism*. 2021;12:13.
51. Daminger A. The cognitive dimension of household labor. *American Sociological Review*. 2019;84:609 – 633.
52. Sinclair J. Being autistic together. *Disability Studies Quarterly*. 2010;30:1.

53. Milton D, Sims T. How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disability & Society*. 2016;31:520–534.
54. Pellicano E, Lawson W, Hall G, et al. “I knew she’d get it, and get me”: Participants’ perspectives of a participatory autism research project. *Autism in Adulthood*. In press: <https://www.liebertpub.com/doi/full/10.1089/aut.2021.0039>
55. Milton D. On the ontological status of autism: The ‘double empathy problem’. *Disability & Society*. 2012;27:883-887.
56. Bertilsdotter Rosqvist H, Brownlow C, O’Dell L. “What’s the point of having friends?” Reformulating notions of the meaning of friends and friendship among autistic people. *Disability Studies Quarterly*. 2015;35:DOI: <http://dx.doi.org/10.18061/dsq.v35i4.3254>
57. Crompton CJ, Hallett S, Ropar D, Flynn E, Fletcher-Watson S. ‘I never realised everybody felt as happy as I do when I am around autistic people’: A thematic analysis of autistic adults’ relationships with autistic and neurotypical friends and family. *Autism*. 2020;24:1438 – 1448.
58. Chevallier C, Kohls G, Troiani V, Brodtkin ES, Schultz RT. The social motivation theory of autism. *Trends Cog Sci*. 2012;16:231–39.
59. Jaswal VK, Akhtar N. Being versus appearing socially uninterested: Challenging assumptions about social motivation in autism. *Behavioral and Brain Sciences*. 2019;42:e82: 1 – 73.
60. Masi A, Diaz AM, Tully L, et al. Impact of the COVID-19 pandemic on the well-being of children with neurodevelopmental disabilities and their parents. *J Paediatr Child Health*. 2021;57:631-636.
61. Cervantes PE, Matheis M, Estabillo J, et al. Trends over a decade in NIH funding for autism spectrum disorder services research. *J Autism Dev Disord*. 2021;51:2751 – 2763.
62. Crane L, Adams F, Harper G, Welch J, Pellicano E. “Something needs to change”: Mental health experiences of young autistic adults in England. *Autism*. 2018;23:477-493.

63. Maddox BB, Crabbe S, Beidas RS, "I wouldn't know where to start": Perspectives from clinicians, agency leaders, and autistic adults on improving community mental health services for autistic adults. *Autism*. 2020;24:919 – 930.
64. Camm-Crosbie L, Bradley L, Shaw R, Baron-Cohen S, Cassidy S. 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*. 2020;23:1431-1441.
65. Rydzewska E, Dunn K, Cooper S-A. Umbrella systematic review of systematic reviews and meta-analyses on comorbid physical conditions in people with autism spectrum disorder. *Br J Psych*. 2020;218:10-19.
66. Weir E, Allison C, Warrier V, Baron-Cohen S. Increased prevalence of non-communicable physical health conditions among autistic adults. *Autism*. 2020;25:681 – 694.
67. MacBeth A, Gumley A. Exploring compassion: a meta-analysis of the association between self-compassion and psychopathology. *Clin Psy Review*. 2012;32:545 – 552.
68. Cai RY, Brown L. Cultivating self-compassion to improve mental health in autistic adults. *Autism in Adulthood*. 2021;3:DOI: 10.1089/aut.2020.0034
69. Pellicano E, Stears M. The hidden inequalities of COVID-19. *Autism*. 2020;24:1309-1310.

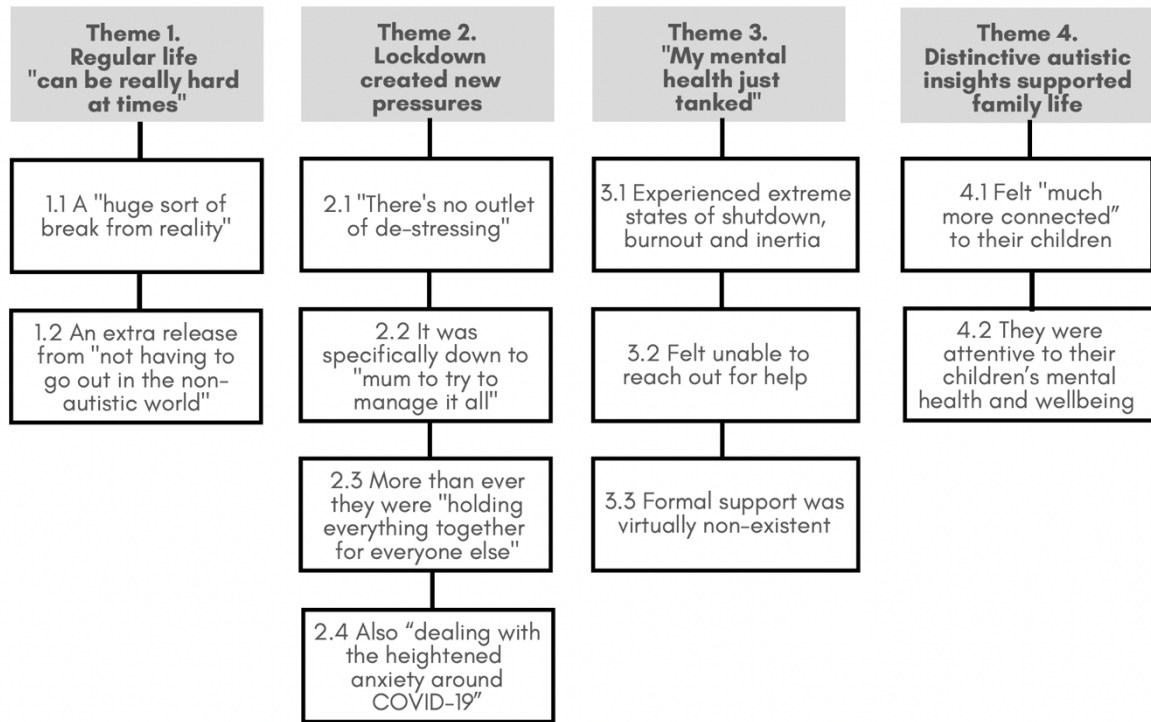


Figure 1. Autistic parents' experiences of life during the initial phase of the COVID-19 pandemic: themes and subthemes.

Table 1. Autistic parents' (n=35) characteristics.

	Mean (SD), Range or N (%)
Age (years)	42.69 (5.58) 32.88 – 54.48
Age at autism diagnosis (years)^a	42.92 (6.63) 28 – 52
Time since diagnosis (years)^a	2.56 (2.73) .20 – 13.51
Gender	
Woman^b	33 (94%)
Man^c	1 (3%)
Non-binary	1 (3%)
Country of residence	
Australia	34 (97%)
United Kingdom	1 (3%)
Predominant racial/ethnic background	
Mixed^d	3 (8%)
White Australian/New Zealand	8 (23%)
White European	24 (68%)
Living arrangements	
With partner & children	26 (74%)
With children only	6 (17%)
With relatives & children	3 (8%)
Highest qualification	
Completed primary school	1 (3%)
Completed Year 10	1 (3%)
Completed high school	4 (11%)
Vocational training	4 (11%)
Undergraduate degree	10 (28%)
Postgraduate degree	15 (43%)
Pre-COVID-19 occupational status	
Part-time employment	5 (14%)
Full-time employment	8 (23%)
Self-employed	5 (14%)
Studying	4 (11%)
Full-time parent	11 (31%)
Unable to work due to disability	2 (6%)
Main sources of household income	
Salary or wages from employment	22 (63%)
Earnings from self-employment	5 (14%)
Government benefits (including disability related payment, carer payment, job seeker payment)	8 (23%)
Lifetime diagnoses of co-occurring conditions^e	
ADHD	14 (40%)
Anxiety disorders	19 (54%)
Autoimmune disorders	8 (23%)
Chronic fatigue syndrome	1 (3%)

Chronic pain	9 (26%)
Depression	23 (66%)
Dyslexia	2 (6%)
Eating disorders	3 (8%)
Gastrointestinal issues	14 (40%)
OCD	1 (3%)
PTSD	11 (31%)
Sleep disorders	6 (17%)

Note: Percentages may not sum to 100% due to rounding issues. ^an=26; ^bIncluded transgender women; ^cIncluded transgender men; ^dParents reporting mixed racial/ethnic backgrounds included White Australian and Middle Eastern, White Australian and Hispanic, White European and Asian. ^eParticipants were asked “Have you ever been diagnosed with any of the following conditions?” and could select all options that applied to them. Percentages therefore do not add to 100.

Table 2. Characteristics of the autistic children (n=55), as reported by autistic parents.

	Mean (SD) Range or N (%)
Number of children in the family	
One child	8 (24%)
Two children	17 (50%)
Three children	7 (20%)
Four children	2 (6%)
Number of autistic children in family	
One child	17 (48%)
Two children	16 (46%)
Three children	2 (6%)
Children's age	10.21 (4.04) 3.98 – 25.33
Children's gender	
Girl	22 (40%)
Boy	30 (54%)
Non-binary	3 (5%)
Co-occurring diagnoses^a	
None	14 (25%)
ADHD/ADD	27 (49%)
Anxiety disorders	29 (53%)
Cerebral palsy	1 (2%)
Depression	3 (5%)
Dyslexia	7 (13%)
Dyspraxia	5 (9%)
Eating disorders	1 (2%)
Epilepsy	1 (2%)
Intellectual disability	1 (2%)
PTSD	2 (4%)
Sleep disorders	6 (11%)
Vision impairment	1 (2%)
Current school setting	
Mainstream with no extra support	16 (29%)
Mainstream with extra support	21 (38%)
Autism-specific class within a mainstream school	1 (2%)
Home-schooled	5 (9%)
Other (e.g., mixed enrolment)	4 (7%)
Not applicable	8 (14%)

Note: Percentages may not sum to 100% due to rounding issues. ^aParticipants could select all options that applied to them. Percentages therefore do not add to 100.