

Exploring the impact of the Covid-19 pandemic on the health & wellbeing of learners with autism

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Summary

This report explores the impact of the Covid-19 pandemic on the health and wellbeing of children and young learners with autism in two specialist schools in the West Midlands region of England. It reveals experiences of social isolation, anxiety, grief and increased tensions at home, as well as feelings of uncertainty and a lack of safety arising due to changing and confusing guidance about Covid-19. It concludes that autistic learners and their parents need:

- service continuity and greater non-academic support from schools when they are closed
- more guidance and support on how to manage autism at home, and to prevent stress, anxiety and other mental health problems
- provision of targeted loss and grief counselling services
- an independent national agency tasked with providing clear guidelines for learning professionals and parents in the event of another pandemic or similar emergency.

1. Introduction

In response to Covid-19, countries worldwide, including the UK, instituted lockdowns. Schools in England were asked to adjust cater for children and young people (CYP) with special education needs (SEN), CYP in care and CYP of keyworkers.

Autism spectrum disorder is generally described as a neurodevelopmental disorder that affects various aspects of individuals' lives including social interaction and communication. It is also characterised by restricted interests and rigid and repetitive behaviours (American Psychiatric Association, 2013). Individuals with autism often struggle to adapt to even the slightest change and can become intensely anxious and unsettled by unexpected change (National Autistic Society, 2020). This is why we wanted to explore the impact of Covid-19 on the health and wellbeing of learners with autism.

According to Cao et al. (2020), there was a negative effect on the emotional wellbeing of learners attending school during the pandemic. UK Youth, a leading national charity, concluded as such in its survey of youth services and young people between 20 and 27 March 2020 into the potential long-term impact of Covid-19 on young people. A total of 252 respondents took part in this survey, 14 per cent of whom were from the West Midlands region of England. The results predicted that the most likely lasting impact of Covid-19 on young people would be increased mental health and wellbeing difficulties (Cao et al., 2020).

These findings were supported by those of another UK charity, YoungMinds, whose study involving 2,111 participants aged 25 and under with a history of mental illness showed that 83 per cent experienced a worsening in their wellbeing. The study also found that 26 per cent of participants were unable to access various forms of mental health support (Dewa et al., 2021). Lockdown has had a direct impact on the mental health and wellbeing of young people in the UK (Fegert et al., 2020). However, the impact of the pandemic on vulnerable individuals living with underlying conditions such as autism is yet to be fully established.

Based on the studies above, it is likely that learners with autism benefited from attending school during lockdown, as routine improves emotional stability. Nevertheless, the disruption of daily routines caused by ever-changing Covid-19 guidance may have triggered frustration and distress in learners with autism (Lee, 2020).

In the early days of the pandemic, with vital services unavailable, constant change and sometimes unclear rules, young people with autism were more disadvantaged than their counterparts (Nyashanu, et al., 2020). This meant that schools that stayed open had to meet both the educational needs and wellbeing needs that would usually have been fulfilled by other services which were forced to close. According to Fraser Butlin (2011), public services have a duty to ensure that no-one, including young people with autism, is disadvantaged as a result of their disabilities. Many autistic CYP have support and communication needs that may not have been met because of the government's approach to managing Covid-19 in England, thus creating significant disadvantage.

1.1 AIMS OF THE RESEARCH

Our research aimed to explore the impact of the pandemic on the health and wellbeing of learners with autism. We wanted to understand how young people with autism were affected by the pandemic and the measures taken in response to it. Other studies conducted in education settings have, because of the complex nature of conducting such studies, tended to exclude special education schools (Istratii & Lewis, 2019).

Our study may not reveal all the challenges experienced by learners with autism during the pandemic. However, it is a starting point and could suggest further avenues of research in order to find effective interventions, particularly for safeguarding the health and wellbeing of young people with autism during a pandemic or other crisis.

2. Methodology

2.1 RESEARCH DESIGN AND SAMPLE

We conducted an explorative qualitative study (EQS) (Pohontsch et al., 2018). EQS seeks to understand the issue being studied rather than providing a conclusive solution to a problem. The study was based on 20 learners with autism aged between 14 and 19. We drew all participants from two specialist schools based in the West Midlands region of England. The schools and the researchers wrote to parents asking for permission for those children who were under 18 to take part in the study. If parents consented, the schools sought consent from the CYP on behalf of the researchers. We recruited learners after they confirmed their willingness to take part. Those aged 18 and over were invited to participate directly by their school.

2.2 DATA COLLECTION

We conducted 20 semi-structured interviews with learners with autism to explore the impact of the pandemic on their health and wellbeing. We thought that this would be the most effective method to elicit honest feedback because it would allow participants to reveal their experiences and help us capture their perspectives (DeJonckheere & Vaughn, 2019). Teachers who were in the same Covid-19 'bubble' as the participants conducted the interviews in order to comply with Covid-19 guidance.

We based the interview guide on a grounded theory approach by Charmaz informed by the transtheoretical model to guide the questions (Johnson et al., 2007; Prochaska & Velicer, 1997). We asked open-ended questions to explore and identify issues. Confidentiality was observed through de-identifying research participants through the use of pseudo identities. Debriefing sessions were held with students, and field notes recorded. We recoded and transcribed interviews verbatim.

2.3 ETHICAL CONSIDERATIONS

We asked participants to read and sign a consent form before they took part in interviews. This included the right to withdraw from the study

without giving a reason. We also gave them an information sheet about the study and the opportunity to ask questions. Nottingham Trent University's institutional review board (ethics committee) reviewed and approved the study.

2.4 DATA ANALYSIS

The interview transcripts were analysed for emergent themes supported by critical quotes using the 2017 computer software program MaxQDA (version 12) to code the transcripts, using a codebook. The researchers developed the codebook, which was expanded as themes were identified and organised to form the final output of the research.

2.5 LIMITATIONS OF THE STUDY

A larger sample that included participants from regions of England other than the West Midlands could help to compare and generalise the issues for learners with autism during lockdown. Our approach allowed us to gather in-depth information about the experiences of some learners with autism during lockdown. A mixed-method approach could explore the issues from different epistemological and ontological positions. The changing situation during this study meant that the picture of young people's experiences was constantly changing. It would be beneficial to explore the impact on learners with autism across the span of the Covid-19 lockdowns.

3. Results

The study revealed that, during lockdown, participants experienced social isolation and anxiety, and felt unsafe and uncertain because of confusing messages about Covid-19. They were also dealing with grief, and with arguments at home.

Figure 3.1
Participant profile

| Sex | Number | Age-range |
|--------|--------|-----------|
| Female | 10 | 14–19 |
| Male | 10 | 14–19 |

3.1 SOCIAL ISOLATION

Participants reported feeling isolated during lockdown because they could not go shopping nor visit their relatives.

'I felt lonely, I couldn't go shopping as usual and I missed seeing my family and friends [...] staying in the house is a boring experience [...] I can't wait for Covid-19 to finish and I can go out shopping again.'

Female learner

'I could not go to see my grandfather who always used to take me to town [...] I just felt that I was trapped in the house forever. I felt unhappy as it seemed the lockdown would go on forever.'

Male learner

3.2 ANXIETY

Participants reported feeling anxious because of what they heard about Covid-19 on the radio and television. News of people being admitted into hospitals triggered anxiety for some. Pre-existing conditions meant that some participants could not wear masks, leading to more anxiety about possible infection.

'I felt so anxious especially when I listen to the radio and television about people being treated in hospitals and some dying [...] It's just scary to be honest [...] No one knows how this will end.'

Male learner

'I cannot wear a mask because of my condition [...] I have anxiety [...] Hearing about Covid-19 made me to feel more anxious because I thought I might be infected by the virus if I was not wearing a mask [...] This was one of the most difficult times of my life.'

Female learner

3.3 CONFUSING MESSAGES ABOUT COVID-19

Participants reported receiving conflicting information about Covid-19, which made them feel uncertain and unsafe. They also referred to evolving news about vaccines.

'I hear a lot of things being said by people about Covid-19 and sometimes you wonder if it is true or false [...] The last time I heard that a Covid-19 vaccine had been found and then you hear that it is not safe, honestly it is confusing.'

Female learner

'I really felt confused to tell the truth [...] About what we were supposed to do during the lockdown to keep ourselves safe [...] I heard my mum also complaining that the information about the Covid-19 pandemic keeps on changing [...] No one has the right information.'

Male learner

3.4 DEALING WITH GRIEF

Participants had to deal with grief especially when they heard that someone they knew had died as a result of Covid-19. This was further complicated because lockdown made it difficult to get support due to scaled down service provision.

'It is difficult when someone you know dies [...], someone I know died during the Covid-19 time [...] but he had another condition. It is hard to think about it. It is worse when you don't know what is happening with the family because of the lockdown.'

Male learner

'It is difficult when you hear that someone you know has been taken to hospital or has died because of Covid-19. I remember feeling very low because a person I knew had been taken to hospital [...] You really feel the pressure because you do not know what will happen [...] It was worse when I just listened to the number of people dying in hospital.'

Female learner

3.5 ARGUMENTS AT HOME

Lockdown meant that participants had to spend more time than usual at home. This led to arguments with other household members and the need for time out of the house.

'The lockdown was so boring I can't afford to go through another lockdown [...] my family spent most of the time together and I could not stop arguing with my young brother [...] I sometimes ended up leaving the house to take a break.'

Male learner

'We literally occupied each other's space. It was really difficult for me as all people were in the house [...] I was always arguing with my little sister because I felt that she was not giving me a break.'

Female learner

4. Discussion

4.1 MAIN FINDINGS

Social isolation can have a lasting and dire effect on the mental health and wellbeing of an individual (Cacioppo & Cacioppo, 2014). Participants felt isolated during lockdown as they could not interact with relatives. This negatively affected their mental health and wellbeing. This could have been further exacerbated by having all the family in the house at the same time and no visitors. The school remained the only place where participants interacted with people beyond their household.

Anxiety has a profound negative impact on the performance of learners (Hopko et al., 2005). This can be worse for learners living with conditions like autism and other learning disabilities (Van Ameringen et al., 2003). Participants in our study were anxious about what they heard about Covid-19 on the radio and television. Hearing about people being hospitalised caused anxiety, especially when it involved someone they knew. This was exacerbated by pre-existing conditions which made it difficult for some participants to wear a mask, leading to anxiety about possible infection.

Effective and clear guidance is important for reassuring and boosting the confidence of learners in any learning environment during a crisis (Rabba et al., 2019). The absence of clear guidance can lead to instability and poor mental wellbeing in autistic learners, leading to other compounding impacts (Adams et al., 2019). Our participants mentioned the fact that government guidance on preventing Covid-19 kept changing, and these ever-changing guidelines made them feel unsure and unsafe.

The death of someone close can lead to stress, anxiety and other triggers for poor mental health (Nyashanu et al., 2020). Lack of support following such a loss can have a long-lasting impact on mental wellbeing (Spinelli et al., 2020). Our participants experienced feelings of grief when they heard that someone they knew had died of Covid-19. This was further complicated by lockdown, which prevented people from meeting and talking about their feelings.

Being at home with family for long periods leads to friction and arguments (Bird et al., 2017); work creates a buffer zone against difficulties arising in the home (Cairney et al, 2019). Lockdown meant that learners with autism had reduced access to their previous network of support, leaving them reliant on the members of their household. Participants reported that being in the house for long periods led to arguments and tensions. Some had to leave the house at times to avoid arguments.

Learners with autism benefit from set routines and predictability. These disruptions were frequent because the Covid-19 guidance kept changing. As autism often occurs alongside other neurodevelopmental, physical and mental health conditions, this group would have benefited from contact with other organisations that work with schools (de Sousa Lima et al., 2020). Those living in homes with no green spaces had less opportunity for outdoor interactions and spent more time indoors. Lockdown restrictions coupled with anxieties about Covid-19 had a negative impact on the mental health and wellbeing of the learners (Ballivian et al,2020).

Singh et al. (2019) suggest that learners would most likely respond to the above with challenging/ aggressive behaviour, mostly directed at their caregivers. This highlights the importance of support services for learners with autism and their families during any lockdown, and the need for service continuity when schools are closed. Parents and autistic learners need more support at home to prevent stress, anxiety and other mental health problems. The UK government should support and acknowledge the work that parents of autistic learners have accomplished in the absence of teachers and other professionals. Policies on supporting autistic learners in times of crisis are needed to prepare for any future disruption.

1.

5. Recommendations & conclusion

5.1 RECOMMENDATIONS

1. Central government, in conjunction with private educational authorities, should provide loss and grief counselling services for parents and autistic learners. Such services alleviate grief and loss (Meagher & Balk, 2013), which in turn protects against chronic depression and anxiety including negative effects on learning (Pauline & Boss, 2009).
2. Central government should provide clear guidance to parents with autistic children to prevent alarm and fear among learners (degli Espinosa et al., 2020).
3. Policies for school closure should consider non-academic support for autistic learners. This could include schools 'checking in' with families regularly and supporting parents with strategies for managing behaviour at home.
4. Central government should support parents to attend online courses on how to manage autism at home.
5. Central government should establish an independent agency that provides clear guidelines relating to autistic learners for learning institutions and parents in the event of a pandemic. Although there are some advisory and inspection agencies such as Ofsted, none are experts in pandemic control and management.

5.2 CONCLUSION

The UK government was right to keep schools open for young people with autism as this helped maintain some routine and normality. However, specialist support services outside schools are needed for parents and learners with autism at such times to reduce and prevent mental health problems.

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