

# Children's lives and rights under lockdown: A Northern Irish perspective by autistic young people

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## Abstract

By June 2021, children and young people had experienced two periods of lockdown and home learning in Northern Ireland. The detrimental impact of these periods of indefinite confinement is wider reaching than reported educational stagnation, with the fundamental rights of childhood: play; rest; and leisure; all adversely implicated. Autistic children's experiences of Covid-19 have been largely absent from current crisis and recovery discourse. This is the first published study to directly and specifically involve autistic children both as research advisors and as research participants in a rights-based participatory study relating to the pandemic. Drawing on concepts of ableist childism and epistemic injustice, this article presents, through Photovoice, the emotional, social and educational experiences of post- primary aged autistic young people in Northern Ireland during the first 2020 lockdown of the Covid-19 pandemic. The project was grounded in a child rights-based approach and was guided by a group of four autistic young advisors aged 11–15. The paper concludes by arguing that government responses to the pandemic, as experienced by autistic young people, act as forms of oppression that prioritises and further embeds normative non-autistic

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structures and responses under the guise of public health necessity.

#### KEYWORDS

ableism, autism, childism, children's rights, COVID-19, participation, UNCRC, UNCRPD

## INTRODUCTION

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) and the United Nations Convention on the Rights of the Child (CRC) (United Nations, 1989) clearly stipulate children's, including autistic children's, substantive rights to education, health services, play, rest and leisure among others (Articles 7, 24, 25, 30 CRPD; Articles 24, 28, 31 CRC). Furthermore, autistic children have the right to support that enables them to develop individually and achieve their fullest possible potential (Article 23 CRC; Article 7 CRPD). Both the CRPD and CRC protect autistic children from discrimination in the exercise of all rights (Article 2 CRC; Article 5 CRPD). Moreover, when decisions are being made for or on behalf of autistic children, due weight must be given to their expressed views during these decision-making processes (Article 12 CRC, Article 7.3 CRPD) and ensure their best interests remain a primary consideration throughout (Article 3 CRC, Article 7.2 CRPD). This process of gathering views must include age-appropriate means and support enabling autistic children to express their views. While all rights are important at all times, rights are most likely to be under risk during times of crisis or emergency.

Not for the first time, the voices of autistic children and young people<sup>1</sup> are absent from representation in health and education services and the Covid-19 pandemic has deepened these inequalities. In 2020, the United Nations Committee on the Rights of the Child (the Committee) voiced serious concerns that marginalised children and young people were undoubtedly adversely impacted by the pandemic, subsequently calling on governments to evaluate how pandemic restrictions were impacting on the health, social, educational, economic and recreational rights of the child. Despite this call, Couper-Kenney and Riddell (2021) noted that many countries were failing to effectively and meaningfully realise the rights of children with disabilities despite their best intentions.

This small qualitative study focusses on actively hearing and understanding the experiences of nine autistic young people aged 11–18 in post-primary mainstream education settings in Northern Ireland (NI) during the first lockdown period beginning March 2020. The study uses Photovoice (Wang & Burris, 1997), a participatory arts-based method, to capture autistic students' lives during lockdown and was co-designed with four autistic young people. Drawing on the concepts of ableism, childism (and specifically introducing ableist childism) and epistemic injustice, this analysis helps provide an authentic understanding of the impact of the pandemic on the needs and rights of autistic young people including how autistic voices could be better included in decision-making practices for autistic young people in times of crisis or emergency.

## CHILDREN'S RIGHTS AND AUTISTIC VOICES

In their statement on the impact of the pandemic on children's rights, the Committee (United Nations Committee on the Rights of the Child, 2020) acknowledged each country's limited financial resources for reviewing the implementation of the CRC during the pandemic, but simultaneously requested countries to ensure that the allocation of resources considered and targeted the best interests of the child. The Committee (United Nations Committee on the Rights of the Child, 2020) also stipulated that planning for any future restrictions be proportionately imposed upon children and only when absolutely necessary.

The Covid-19 pandemic has undoubtedly impacted the extent to which autistic young people have been able to access their rights, including rights to education, development, play, rest and leisure. These activities, all constituting a day in school, were relocated to the home during both lockdowns thereby blurring the clearly delineated lines of home and school for autistic young people (Canning & Robinson, 2021). The Committee (United Nations Committee on the Rights of the Child, 2020) urged governments to ensure that remote-learning plans did not exacerbate existing inequalities among children and that online learning was not equated to, nor intended to replace student–teacher interaction. Online learning is acknowledged by the Committee (United Nations Committee on the Rights of the Child, 2020) as a purposeful and creative substitute to classroom learning, but one which poses challenges for children whose parents lack confidence in supporting home learning and for families experiencing digital poverty (Ferguson, 2021). In NI, Walsh et al. (2020) online survey noted that 50% of the 2035 respondents were families where children did not have access to their own device for remote-learning.

Finally, the Committee (2020) implored governments to explore innovative solutions to enable children to resume enjoyment of their rights to rest, leisure and recreation. These solutions include the provision of child-friendly cultural and artistic activities on TV, radio, online and supervised daily outdoor activities that respect physical distance and hygiene protocols.

Extensive attempts were made to facilitate this in the UK through the use of BBC bitesize programmes, celebrity led recreational programmes, with the Northern Ireland Curriculum authority, CCEA, teaming up with BBC NI to devise interactive activity programming (Walsh et al., 2020). These recreational activities were more often prioritised by the parents of autistic young people in Canning and Robinson's (2020, p.11) study as they 'valued their child's mental health above the need for completing schoolwork'.

The global survey of over 26 000 young people from across 137 countries about their 'Life Under Coronavirus' (Lundy et al., 2021) explores the impact of the pandemic on the lives of children, however, there is limited research specifically interrogating the experiences of autistic young people during this pandemic. Even Canning and Robinson's (2021) highly informative work focusses solely on parents' experiences of home-schooling their autistic children, not autistic children and young people's experiences themselves. Pisula et al. (2017) caution that parents' representations of their autistic children's experiences should not take the place of representing true autistic voice.

## ABLEIST CHILDISM AND EPISTEMIC INJUSTICE IN TIMES OF CRISIS OR EMERGENCY

The continuously emerging literature on the pandemic highlights a range of impacts on the lives of children and young people, disproportionately felt by certain 'vulnerable' groups (Driscoll et al., 2021; Lundy et al., 2021). Existing literature on the experiences of autistic

young people with respect to the pandemic, however, makes limited specific reference to the UNCRC or UNCRPD (but see Couper-Kenney & Riddell, 2021), and has not incorporated a participatory or rights-based research approach, instead focusing on the experiences and perspectives of parents and/or through an individualised lens (Jacques et al., 2021; Musa et al., 2021). The Committee has previously observed that children's participation in decision-making processes during times of national or global crisis or emergencies, and recovery thereafter 'helps them to regain control over their lives, contributes to rehabilitation, develops organisational skills and strengthens a sense of identity' (UN, 2009, para. 127). Involvement in decision-making at times of crisis or emergency as well as recovery planning is critical in holding government bodies to account and ensuring that governmental agencies and services are able to respond more quickly and effectively to children's needs (Lundy et al., 2021).

It could be argued that the exclusion of autistic young people from decision-making processes at times of crisis or emergency is tantamount to what we refer to here as ableist childism; the intersection between ableism (Goodley, 2014; Wolbring, 2018) and childism (Adami & Dineen, 2021; Yung-Bruehl, 2012), that is, as a form of structural discrimination and based on prejudicial ideas about lack of or limited capacity for reasons due to childhood and/or disability. This paper responds to Adami and Dineen's call for an intersectional lens on how children are affected by overlapping systems of oppression (Adami & Dineen, 2021, p.356). The twin concepts of ableism and childism raise fundamental questions about larger social systems and structures where discriminatory experiences of children with disabilities are perceived as inevitable because of something that is wrong with them rather than the world around them. In so doing, ableism and childism, in their respective domains, seek to challenge existing norms and social structures that have traditionally excluded or silenced disabled people and children. Core themes of ableism and childism can be found across the fields of traditional childhood and disability research, policy and practice (Byrne, 2012). As Curran and Runswick-Cole (2014) have noted more broadly, the perceived 'tragedy' of impairment, alongside a presumed lack of capacity associated with age has distracted or indeed discouraged professionals from direct engagement with children with disabilities themselves. This is perpetuated by prejudicial assumptions that where direct engagement with children with disabilities might be under consideration, this would likely be too expensive or time consuming (Byrne & Kelly, 2015). By bringing ableism and childism together we seek to question and challenge existing norms, systems and structures through the lens of ableist childism recognising the explicit intersection between disability and childhood and acknowledging the distinctive experiences of children with disabilities benchmarked against both the CRC and CRPD. This is not to ignore or undermine valuable existing work, for example, Curran and Runswick-Cole (2014) identification of 'disabled children's childhood studies', but seeks to offer an alternative for discussion that forefronts and names deeply embedded inequalities as discrimination (Adami & Dineen, 2021) against a rights-based backdrop.

Omitting the voices of children and young people with disabilities from decision-making processes also pertains to epistemic injustice that is both testimonial<sup>2</sup> and hermeneutical<sup>3</sup> (Byrne, 2022; Fricker, 2007; Kotzee, 2017). The concept of epistemic injustice is easily applied to the autistic student population of Northern Ireland where autism is delineated as

a communication and social interaction difficulty on a school's special educational register (Department of Education, 2019) deeming autism as both a 'difficulty' and 'special'. When an educational stakeholder assumes that an autistic student cannot articulate their views, testimonial injustice occurs. If autistic voice is pursued through a means that creates barriers to communication, then this renders the autistic student as voiceless and unheard and reinforces hermeneutical injustice. For example, during annual review meetings in NI, an autistic student may be asked to represent themselves in front of several unfamiliar adult stakeholders, creating an intimidating environment for the autistic student and one in which they are unlikely to effectively represent themselves.

If autistic young people are to participate in decision-making processes during situations of crisis and emergency, while their rights are protected and promoted, then associated decision-making processes must uphold autistic children's rights and be guided by autistic young people. Illuminating the perspectives of autistic young people, valuing their contribution and acting on the insider knowledge gleaned will ward off instances of epistemic injustice.

## METHODOLOGY

This study is situated in the transformative paradigm in light of the combination of a child's rights-based approach within an epistemic injustice framework (Fricker, 2007; Mertens, 2009). To this end the child rights-based research approach builds upon the work pioneered by Lundy and McEvoy (2012) (see also Lundy et al., 2021) and focuses, firstly, on autistic young people's enjoyment of their rights during a time of crisis or emergency; and secondly, involving autistic young people throughout the study alongside the adult researchers and contributing to the research questions, methods, interpretation of data and dissemination. This research focusses on the emancipation of its participants by not only focussing on the voices and experiences of autistic young people, but by acting upon the new knowledge uncovered and attempting to change how stakeholders perceive and respond to the needs of autistic young people. The autistic young people in this research were encouraged to convey their experiences during lockdown using a research method that could bypass a range of possible barriers impeding their capacity to communicate their lived experience. Upholding the principles of transformative research (Mertens, 2009), where autistic young people are encouraged to illuminate their experiences and to realise their rights, the adult researchers must then ensure that autistic young people's participation results in meaningful action by stakeholders who play an active role in decision-making for autistic young people.

### Young people's advisory group (YPAG)

Foregrounding autistic voice, the project was guided by four young autistic advisors (two girls and two boys) from across Northern Ireland aged between 11 and 15 forming a Young People's Research Advisory Group (YPAG). The four young advisors were recruited through autistic networks in Northern Ireland with two attending one of the adult researcher's school. The YPAG and two adult researchers jointly refined the project aims and developed the questions that would enable their participating peers to visually capture their experiences during lockdown. An individual introductory Zoom meeting was arranged between the adult researcher and each young advisor to confirm their understanding of the study and their commitment to participation as

an advisor to the study. This involved three further online Zoom meetings with the YPAG, two before the data collection process and one after all the data had been collated. Agendas for each meeting were sent in advance so each young advisor would know what to expect.

The first YPAG meeting actively considered the issues facing autistic young people during the pandemic and collectively devised three research questions:

Question 1: What were your experiences and emotions during lockdown?

Question 2: How have you adjusted to lockdown during this time?

Question 3: What have adults done that has helped you during lockdown?

Photovoice was then introduced as a potential research method. Requiring only a basic knowledge of photography and considering the widespread use of Smartphone 'selfies' by the adolescent population, Photovoice presents as a particularly useful and rich method for accessing the perspectives of autistic young people (O'Hagan, 2020; Teti et al., 2016). To ensure the YPAG had the knowledge to consider its use, sample Photovoices were presented and the YPAG then created their own Photovoices to examine and ensure its suitability for this study. This further developed the YPAG's understanding of Photovoice and built capacity for their later analysis and interpretation of the participants' photographs. Discussion points for the individual post-Photovoice interviews were also formulated. The third YPAG meeting engaged the platform Padlet to enable the YPAG to collectively analyse each participant's photographs and then group the photographs into emerging themes for discussion.

Other methods of data collection such as interviews and focus groups were considered, however, the YPAG felt Photovoice would elicit the experiences of young autistic people and would enable urgent and timely data collection. A limitation of Photovoice is the unpredictability of the outcome of any Photovoice and whether it instigates transformative change, as is its goal. Where no beneficial change occurs post-data collection, a Photovoice simply exists as photo elicitation (Rose, 2012). To avoid this, the adult researchers in this study were charged with the role of bringing the completed Photovoice to a wider educational stakeholder audience as is discussed later.

## Research participants

Post-primary aged participants (11–18) from all school sectors (mainstream and special) were recruited. A poster for the research project was widely shared through the online platforms of Facebook and Twitter. The study was also advertised via an email-drop to the Education Authority's Autism Advisory and Intervention Service (AAIS) and across various Special Education networks in NI. Ethical approval for the study was received from the School of Social Sciences, Education and Social Work at Queen's University Belfast in May 2020. Young people and their parents who expressed interest were provided with accessible information sheets and consent forms detailing the aims and objective of the study, their role, nature of voluntary participation, and how the data would be used and stored. All participants who returned completed forms consenting to take part were included in the research. Five participants committed to the study alongside the four young advisors who also participated in the Photovoice (See Table 1 below).

We were conscious that exploring what life is like in lockdown for young autistic people could be potentially experienced as sensitive, especially if they were finding lockdown disruptive, challenging or upsetting. Equally we were aware that participation in the project could be experienced as an outlet and a means of expression. We did not ask young people to specifically divulge information that might be difficult. We worked with the YPAG to ensure that our prompts and



**TABLE 1** Breakdown of photovoice participants and data collection

Participant	Gender	Year group	No of Photos produced	Member of YPAG
Stephen	Male	Year 9	6	No
Darach	Male	Year 11	8	Yes
Sam	Male	Year 10	3	No
James	Male	Year 9	6	No
Patricia	Female	Year 10	4	Yes
Joe	Male	Year 11	4	Yes
Jarlath	Male	Year 9	3	No
Ellen	Female	Year 10	7	No
Eimhear	Female	Year 8	7	Yes

guidance on taking photographs was accessible, child friendly and sensitive to any potential distress or other adverse effects. A distress protocol was also developed for the study ready to be invoked if a young person became upset. This did not need to be activated. All young people who took part were informed that participation was entirely voluntary and that they could withdraw at any time. All participants wished to use their real first names.

It is important to note the limitations of the study. Despite the recruitment strategy actively including non-mainstream schools, the study only encompasses autistic young people from five mainstream schools. It is important to note that research spaces that set out to be inclusive can also be exclusive and lack diversity in other ways (Liddiard et al., 2019).

Autistic young people are not homogenous and occupy diverse educational and social spaces. Similarly, the research participants, and indeed advisors, were verbal. This is not to say that they represent, or can represent, the experiences of autistic young people who communicate in other, non-verbal, ways (Chinn & Pelletier, 2020). Due to pandemic restrictions at the time of the study, we also relied on autistic participants having access to digital technology. Therefore, this study is not representative of all autistic young people in post-primary school in NI.

The onus remains on us as researchers to find ways of engaging autistic young people who are harder to reach, especially in times of crisis and emergency. Nonetheless the value of the study is in providing a snapshot of autistic young people's experiences of their rights during lockdown and to convey their experiences in ways they might not otherwise have felt able to.

## Data collection

Data collection took place over a 6-week period in May, June and July 2020 during which time lockdown restrictions were eased for the first time in Northern Ireland. Three PowerPoint presentations designed by the research team were emailed to participants to guide them through the project in a step-by-step process. The first presentation introduced the research team, explained the purpose of the study and introduced the concept of Photovoice. Each participant was asked to email the research team to confirm they had read and understood the first presentation, they were also encouraged to email any questions to clarify their understanding. Once the research team received the participants' replies, the second presentation was emailed. This presentation was a short accessible guide to documentary photography focussing on how the composition of photographs could be used to portray meaning. Once participants replied to confirm they

had understood this guide to photography, the third and final presentation was emailed. This contained the research questions and detailed instructions of the Photovoice task.

Once the participants had read and understood all three presentations, they were then asked to use their smartphones to document their lives in lockdown. Participants emailed their photographs to the research team with short descriptions of the meaning of the photographs. The adult researchers then conducted follow-up Zoom interviews with each participant to further clarify the meaning of each photograph.

## RESULTS AND DISCUSSION

The nine participants captured 48 photographs for the Photovoice. In the final YPAG meeting and using the platform Padlet, each young advisor randomly selected a photograph and the corresponding quote was then presented on screen by the researchers. The young advisors then led the discussion on how each photograph could be thematically categorised.

This continued in turn until all 48 photographs were analysed culminating in three headings/main themes with six sub-themes categorised according to the original three research questions. The YPAG then discussed the wider findings of the research resulting in the recommendations from the Photovoice.

## FINDINGS

The first heading *Emotional and Social Well-being* is divided into two sub-themes *fear and uncertainty* and *isolation* and refers to part of the first research question depicting the emotions that young people experienced since the emergence of the pandemic. The second heading *Pressures of Home-Schooling* is a theme in its own right also referring to the first research question depicting the challenges of lockdown. The third and final heading *Coping Strategies and Support* relates to both the second and third research questions in terms of what young people identified as being helpful during lockdown and includes three subthemes: *relationships*; *hobbies* and *the importance of being outdoors*. It is not possible to include all 48 photographs and so the photographs most connected to each theme as identified by the YPAG are presented.

## THEME 1: EMOTIONAL AND SOCIAL WELL-BEING

### Fear and uncertainty

Like all young people, the participants in this study were worried about what was going to happen and how long the pandemic was going to last.





[Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/cbs.12651)]

‘The beach goes out a bit so you can’t really see what’s at the end, this is like my current situation and the world’s current situation, we don’t know what’s at the end and we don’t know what’s coming for us and what’s coming for me. I don’t really know what’s at the end of the road. It’s uncertain.’ (Darach)

As lockdown restrictions eased, some young people were able to go out, however, this continued to contribute to anxiety when adults did not appear to take social distancing measures seriously.



[Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/cbs.12651)]

‘...The stress of catching Covid-19...and that Mummy could potentially die. There were situations when I was going to Gaelic even the coaches were standing shoulder to shoulder. I was so annoyed as I had gone there in confidence thinking social distancing like a sort of lockdown. I found it very difficult at times. The gravestone represents the danger of not being careful.’ (Sam)

## Isolation

Young people reported feeling ‘low’, ‘depressed’ and ‘isolated’ during lockdown. For the autistic young people in this study, their isolation manifested itself in the amount of time they now spent alone and heightened their levels of stress and anxiety. This was mirrored in Canning and Robinson (2021) study where parents reported a deterioration in their children’s mental health well-being during home-learning. The young people in this study felt overwhelmed by spending so much time with their family in restricted spaces. Ellen described private spaces as a necessity to keep bubbling anxiety under control.



[Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/cbs.12651)]

'I'm usually in my room all day. I know if I come downstairs to socialise with everybody I would get stressed. Sometimes my stress and anxiety take over and it makes me say things I don't mean.' (Ellen)



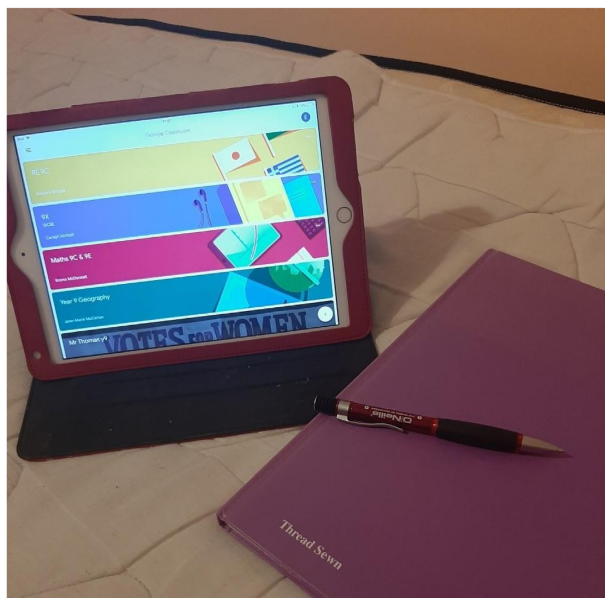
[Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/cbs.12651)]

Eimhear presented herself as feeling very small in the face of something that was overwhelming, comparing the coronavirus to a seagull 'because I sometimes feel like lockdown is eating up all my social life.' (Eimhear)

## THEME 2: PRESSURES OF HOME-SCHOOLING

All nine research participants were determined to portray how difficult school became during lockdown. They consistently referred to the stress and pressure of home-schooling and that having to engage with new educational platforms across multiple subjects could be overwhelming at times marrying with Canning and Robinson's (2021) concerns over blurring the lines

between home and school. This is further exacerbated by Ferguson (2021) unearthing that many parents lacked digital confidence during home-schooling and that digital poverty pervaded 50% of the 2035 homes surveyed in Northern Ireland (Walsh et al., 2020). Participants keenly felt that they were not growing intellectually during this time. No sub-sections were selected for this theme so that each response could be considered individually.



[Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

‘That’s google classroom and these are some of my classes but my book is closed because I’m trying to represent that I’ve been finding work really stressful and I have not been able to do it. I’ve been able to do the stuff that I find easy but I find maths and science really stressful.’

(Ellen)

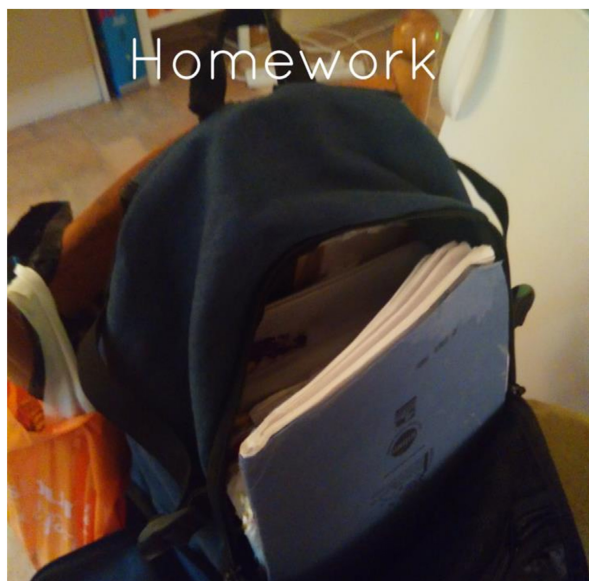


[Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/cbs.12651)]

'I felt like my hand was tied by having to check all these different tasks on different platforms, some projects on MyMaths, some on google classroom, some as notifications, some as assignments. You don't know where to find work and teachers expected you to remember exactly what would happen and to check at different times. It actually would take so much time to look for your work [that] you wouldn't have very much time left to do it in the end or anything else' (Sam)

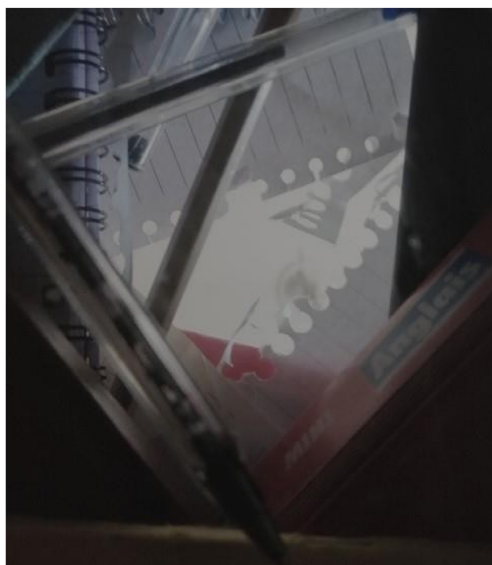
James confirmed this by stating that not having his learning support teacher made it impossible for him to do maths at home due to his dyscalculia while Jarlath used a photograph to demonstrate just how much homework was part of his life during lockdown.





[Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/cbs.12651)]

This feeling of not quite knowing what to prioritise or what to focus on was shared by another young person. Sam, for example, shared a picture of books and pens covering each other.



[Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/cbs.12651)]

‘It’s as if you are covered by all the books, like they’re traps. I was finding it very difficult with all the work coming in. All the writing and reading coming in was overwhelming and there was no clarity.’ (Sam)





[Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/cbs.12651)]

“I’ve been trying to get out every day because I feel like it clears my head. My dog is just in front of that cornfield and everyday when I cycle past, I look up and I see it getting bigger everyday. I don’t think I am growing as much intellectually but the cornfields will keep growing”. (James)

Masonbrink and Hurley (2020) rate the loss of resources and in-person education for children and young people as critical. Crane et al. (2021) specifically consider children with disabilities and demonstrate how for them education has been significantly compromised in multiple and intersecting ways. Adami and Dineen’s (2021) discourse on childism and ableism reiterates this concern with Ferguson (2021) noting that the absence of young people’s voices during this pandemic is tantamount to their exclusion from their own education. This makes the presentation of these experiences crucial to understanding the challenges faced by these autistic young people in Northern Ireland during the first lockdown and needs to be acknowledged by all educational stakeholders when planning educational redress or recovery.

### THEME 3: COPING STRATEGIES AND SUPPORT

The findings relating to the second research question in terms of how young people adjusted to lockdown evidence the importance of Lundy et al. (2021) stipulation for including children’s views regarding decision-making and demonstrates how autistic voice could influence future decision-making regarding lockdown for autistic young people. These young people did learn to adjust and were able to comment eloquently on what worked and did not work during this time. This included consideration of the third research question in terms of how adults helped during lockdown and was prioritised as the first of three sub-themes in this section: *relationships*; *hobbies* and *the importance of being outdoors*.

## Relationships

Families were usually the first and sometimes only point of contact for young people in the study. Young people shared their anxieties with parents who were able to provide reassurance and help the young people navigate the challenges that arose. However, the participants were keen to point out that sometimes the key family member that they could talk to did not live in their house and therefore, future restrictions needed to acknowledge that autistic young people needed to have access to their wider family circles for support and should be entitled to visit these people in spite of restrictions. The voices of the young people in this study clearly echo The Committee's (2020) stipulation that planning for any future restrictions be proportionately imposed upon children upholding the principle of their best interests.



[Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

'I chat with my Mum on a day to day basis. She knows what would make me anxious most of the time, she can almost predict when I'm going to be anxious. If I'm worried about something, I can just talk to her about it and she can help me. My mum can calm me down, give me a hug, get the weighted blanket or go on the swings.' (Patricia)



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'I did this picture with my Granda. Whenever I see this I remember about my baby cousin and how I was always happy holding him. I hope I get to see him soon. My Granda is an artist and he helps me with tips. I'm still working on this and it's better now than before.' (Ellen)

Prior to the pandemic, all participants had access to support professionals in health and/or education. It was crucially important for the participants to continue to have this support during lockdown, however, as the nature of the support changed due to restrictions so did its therapeutic benefit. The now virtual nature of this support brought its own challenges and made it more difficult to engage with counsellors, etc. and thereby calls into question whether the United Kingdom was failing to effectively realise the rights of children with disabilities in accessing their statutory healthcare (Couper-Kenney & Riddell, 2021).



[Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

'My therapist phones me every week or every two weeks. Talking... is problem solving. It's more than just conversation. If I have a problem or am worried about something I talk to her and come up with the solution. But on the phone you can't see her reaction. You can only hear it, normally I would have a bit of time to catch up with her but it's harder to talk on the phone than in person. The phone calls are shorter than normal appointments so you can't go into as much detail.' (Patricia)

## Hobbies

All the young people in the study had drawn on existing hobbies or developed new hobbies as a coping strategy during lockdown. This provided a source of distraction, routine and instilled a sense of calmness. They viewed these hobbies as crucial to their mental health well-being but felt that schools did not acknowledge this importance and overloaded their days with schoolwork leaving little time for minding their mental health. Canning and Robinson (2021) concur acknowledging that while schools prioritised remote learning, parents of autistic children prioritised their children's mental health well-being over schoolwork completion and arranged their children's home-school days to reflect this by incorporating time for hobbies and other activities.



[Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/cbs.12651)]

‘Baking helps me relax and it helps me forget about the things I’m worrying about. I’ve been worrying a lot.’ (Ellen)



[Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/cbs.12651)]

‘When we had school at the start, I found it quite hard. I needed routine and I needed structure. I needed to know. I’m not the sort of person who can do school one day at 9am and then 4pm the next day. I need things to be the same and predictable. These are all the objects of my routine.’

(Patricia)



## Being outside

In some instances, the young people in this study had to devise their own support mechanisms and having time outside everyday was a way of managing stress during lockdown. The young people built time outside into the new routine of their days and this was a welcome and necessary reprieve to online learning and being confined to home. This theme was heavily discussed by the YPAG and finally formed one of the final recommendations of the study.



[Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

“It’s blurred in the background and pixelated in areas because at times I have found myself very, very stressed and there was a lot of frustration and anger building up. The bike is very clear because I find a lot of solace or it’ll be like a great escape to go on a bike ride. It was so good to have my bike to have the opportunity to escape from all the school work”. (Sam)





[Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/cbs.12651)]

“This place is a sanctuary for me.” (Darach).

Masonbrink and Hurley (2020) have insisted that educational stakeholders address the psychological impact of the pandemic on children and young people. Dimitrellou and Male (2020) note that the starting point for addressing this impact is to listen to the perspectives of young people thereby empowering them. Including them in this dialogue and process has the potential to rectify their futures (Couper-Kenney & Riddell, 2021). This study aligns with Couper-Kenney and Riddell (2021) in uncovering the importance of relationships and outdoor activity during the first lockdown. Crane et al. (2021) adds further support to this by proposing that a holistic approach to education be adopted should future lockdowns whereby the needs of more vulnerable learners in either in class or at home are prioritised over academic curriculum.

Thus far these photographs act as documentary photography or photo elicitation and cannot be called a Photovoice until meaningful change has been actioned by stakeholders as a result of the lived experiences depicted (Rose, 2012). Both Lundy et al. (2021) and Couper-Kenney and Riddell (2021) highlight the fundamental right of the consideration of children's views when decisions are being made for them. As such, the YPAG's recommendations from this study and a selection of the photographs were presented to the Education Committee of the Northern Ireland Assembly in December 2020, a timely 3 weeks before a second closure of schools in Northern Ireland. During this second lockdown, the research recommendations were presented to the Education and Training Inspectorate of Northern Ireland and also published in a Northern Irish teachers' union magazine 'PrintOut' in February 2021. This meant that three different groups of educational stakeholders were asked to consider these recommendations as revised plans for home-learning were being rolled out in Northern Ireland achieving the ultimate goal of Photovoice, transformative change and the emancipation of the participating group, in this case, autistic young people.

## CONCLUSION

The paper responds to Adami and Dineen's (2021) call for an intersectional lens on how children are affected by overlapping systems of oppression. We do this by exploring systems of oppression in the context of a specific crisis or emergency; the COVID-19 pandemic and how the symptoms of oppression can be manifested as 'symptoms' of autism. The positioning of children with disabilities—and autistic young people—as rights-holders has been slow to permeate into policy and practice (Hodge et al., 2022). The adoption of the CRPD as a disability specific human rights treaty and related work by the Committee, under the CRC, to firmly establish children with disabilities as rights-holders and clarify how rights are to be applied in a way that reflects the intersectionality of disability and childhood, is a critical step forward. However, this also requires active work to highlight the various ways in which rights are being operationalised or undermined, particularly in the context of crisis or emergency and subsequent recovery discourse. It is in this vein that the present paper is situated.

Children's right to be heard is not 'the gift of adults' (Lundy, 2007), rendering it optional in times of crisis and emergencies. As Lundy et al. (2021) emphasise, children's rights are not a dispensable luxury but an indispensable entitlement. This paper adds to the literature by presenting, for the first time, autistic young people's experiences of lives under lockdown in their own images and words. The findings indicate that autistic young people's rights have been undermined across education, development, health, play, rest and leisure in particular. Furthermore, there is no evidence that their best interests have been a primary consideration when decisions have been made about lockdown restrictions and remote learning. These experiences can be understood through the lens of ableist childism; as a prejudice based on assumptions of what autistic children can and cannot do along with a disregard for the ways in which government decisions relating to the pandemic have disproportionately impacted on autistic young people and failed to respect their rights. Adami and Dineen (2021, p. 366) have highlighted how government decisions around policies developed during the pandemic gave precedence to adult interests, needs and power in issues affecting children. They not only gave precedence to adult interests and needs, but to the interests of non-autistic adult interests and needs. This can be identified in the shift to remote learning without consideration of the challenges this might pose for autistic young people and the additional sensory overload that can arise. Young people in this study spoke of heightened anxiety and stress, and some even referred to the impact of 'my stress' (Ellen). This is an example of how active decisions made by non-autistic adults can lead to situations that can exacerbate anxiety but also become internalised. Similarly, young people's worries about the uncertainty surrounding the pandemic highlight the need for adults to provide accessible, age-appropriate information. The impact on autistic young people's emotional well-being of not being able to see key adults in their lives, is indicative of the need for non-autistic adults in government structures to take the best interests of the child into account when making decisions about responses to crisis or emergency. When access to these wider key people is restricted, levels of isolation and loneliness heighten and contribute to a deterioration in mental health well-being, a vulnerability already associated with autistic young people. Furthermore, impersonal online interactions do not have the same therapeutic benefit as key face-to-face interactions where clinical or educational interventions take place and these poor substitutions can actually worsen mental health well-being.

There are several points which autistic young people wish to be considered with respect to online learning and managing school at home. When in school, autistic young people usually have their learning differentiated by the class teacher within the classroom and then further

scaffolded by learning support teams including classroom assistants and specialist teachers. When schools closed during lockdown, these support mechanisms were lost while autistic young people, without warning, had to navigate inconsistently used learning platforms.

Schoolwork became overwhelming and ambiguous for the autistic young person and deadlines mounted. These platforms took an inordinate amount of time to navigate, a factor not considered by teachers and this resulted in some of the participants of this study engaging in 12-h school days. Young people felt overloaded by their teachers and there was limited regard for how overwhelmed the students felt by the volume of work set.

Taken together, the experiences of young autistic people presented here raises broader questions about social structures and systems. More specifically it shines a light on the prejudices that underpin government choices in the pandemic and the subsequent exclusion of autistic young people from decision-making processes. Ableist childism serves to reaffirm existing norms during the pandemic through prioritising and embedding normative non-autistic structures and responses under the guise of public health necessity. Such an approach maintains and exacerbates existing inequalities and perpetuates epistemic injustice. In challenging testimonial injustice (Fricker, 2007) by pedestalling insider autistic knowledge while circumventing hermeneutical injustice (Kotzee, 2017) by choosing Photovoice methodology, this study has enabled the young autistic experts to convey their experiences and concerns and has produced useful, authentic knowledge and understanding (Kotzee, 2017) that can guide future provisions for autistic students. The use of an online Photovoice demonstrates how transformative change can still be achieved during times of restrictions, with previously deemed inaccessible participants. This study goes further in engaging stakeholder audiences across micro and macro online platforms ensuring emancipation and regard for those participants and the wider groups they represent cementing the outcome of Photovoice.

The autistic young people in the study shared a common goal to illuminate the challenges they faced during this time so that should a future crisis or emergency occur, these challenges as triggered by government responses could be taken into consideration when lockdown arrangements and restrictions were being shaped for autistic young people:

“There is not one cure for this, we need to look at things individually and figure out things for each different person.” (Joe-YPAG)

The scope of this Photovoice is limited to Northern Irish context of mainstream post-primary schools. However, through this research our autistic young people have encapsulated their experiences of lockdown demonstrating the disproportionate difficulties they faced when compared to their peers and that their isolation during lockdown contributed to their feelings of loneliness and fear. Moving forward, there is one clear and consistent message from these autistic young people with regard to shaping lockdown for autistic young people:

“During a pandemic, you cannot leave people with autism without help, without support.” (Eimhear—YPAG)

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## CONFLICT OF INTEREST

None.

## DATA AVAILABILITY STATEMENT


The data that support the findings of this study are openly available in [repository name] at [DOI].

## ETHICS STATEMENT

The project received ethical approval from the School of Social Sciences, Education and Social Work Ethics Committee at Queen's University Belfast.

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## ENDNOTES

- <sup>1</sup> From here the term 'autistic young people' will be used to refer to autistic children and young people up to the age of 18 unless referred to otherwise in original literature.
- <sup>2</sup> Testimonial injustice uses status identifiers to construct power imbalances between the speaker and the hearer, and so in the context of education, for example, the imbalance is between the student and educator, and in favour of the educator who assumes a position of knowledge and power over the student thereby disregarding the student's perspectives or wishes.
- <sup>3</sup> Hermeneutical injustice in education occurs when student voice is sought using a means that is actually inaccessible to the student and therefore ineffective at meaningfully conveying their perspective or lived experience.

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